Traveller gypsies and primary health care in East London.

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TRAVELLER GYPSIES AND PRIMARY HEALTH CARE

IN EAST LONDON

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ABSTRACT

A three-part study of Traveller-Gypsy primary health care needs and provision of preventive services was undertaken in Hackney, East London between July 1987 and November 1990. One part of the study assessed the role of primary health care providers. It included a postal questionnaire to east London general practitioners assessing their willingness to see Traveller patients and the problems they perceived in providing health care for this community. This part of the study also surveyed the work of the Travellers' health visitor. The second part was a primary care-based survey of 152 children and 93 adult Travellers and 188 children and 101 controls from the settled population. Data was collected on childhood immunisation and cervical smear status, prevalence of cardiovascular risk factors and alcohol consumption, birth weight, child growth and use of a hand-held medical record. The third part consisted of in-depth interviews with 31 adult Travellers exploring their views of health and health care.

The study found that ten percent of general practitioners in east London would not accept Travellers even as temporary residents. Of those general practitioners who did have Traveller patients, most experienced problems with Travellers' use of appointment systems, providing continuity of care and lack of information about past medical history. The Travellers' health visitor role was wide with insufficient administrative support or setting of priorities. Lower immunisation and cervical smear and higher smoking rates were found in the Traveller sample, but the prevalence of hypertension, diabetes, hypercholesterolaemia and alcohol abuse was not greater than in the control sample. There was no difference in the proportion of low birth weight babies or underweight children. One quarter of the hand-held medical records given to patients were used at least once, although none outside the study area. When interviewed Travellers emphasised environmental disease aetiologies, recognised lifestyle factors, had a selective view of immunisation and reported widespread problems with access to health care.

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Acknowledgements

Oonagh Sweeny followed up non-responders and collated results in the questionnaire survey of general practitioners. In the epidemiological part of the study her successor, Teresa Vaclavik, transferred data from cards to the database, followed up incomplete data and validated parental reports of immunisation with other sources. She also participated in discussion of the results. The questionnaire to Travellers was administered by Teresa Vaclavik and she participated in the modification of questions in the pilot phase and initial discussion of the results.

The survey of the Travellers' health visitor role was collaborative, with the participation of Linda Dodge, Joan Miller and Lesley Morrison. I participated in joint planning and design of the work, analysis of the data collected and formulation of conclusions and recommendations. I was not involved in data collection. Allison Streetly collaborated in analysis and interpretation of immunisation data. Random plasma glucose was determined by the Homerton Hospital chemical pathology laboratory, random serum cholesterol by the St Bartholomew's Hospital lipid laboratory and poliovirus antibodies by the St Bartholomew's Hospital virology laboratory.

Howard Cuckle advised on design of the epidemiological part of the study and Malcom Law advised on interpretation of cardiovascular risk data. Ann Woolett and William Bell advised on design of the Traveller questionnaire and interview training. Peter Brown gave statistical guidance. Ann Bagehot and Liz Kwast started off my bibliography and advised me on research needs in the area of Traveller health care. David Armstrong advised on the interpretation of interview data and the theoretical context of the whole study. Jan Savage encouraged me to explore an anthropological interpretation of Traveller ethnicity and supported me in the dark hours. Eric Aangard translated Swedish articles and Marika Feder translated Hungarian and German articles. Lesley Southgate supervised writing up of the thesis.

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CHAPTER ONE: INTRODUCTION

This dissertation is based on a study of Traveller-Gypsies and health care professionals in Hackney, East London. It presents an original analysis of health care needs of Travellers in an inner city area. The study contributes to local and national discussion of Travellers' health care and to a debate about appropriate health care research methods for marginal groups.

The original motivation behind the study came from working in a practice used by Traveller families and my perception that they were getting a poor service. I questioned whether their needs for and access to preventive and screening services differed from those of other patients. The study started with a questionnaire survey of East London general practitioners to assess attitudes towards Travellers. Subsequent data collection in three primary care settings suggested that Travellers were less likely to complete childhood immunisations and have cervical smears and were more likely to smoke than the settled population. These results, coupled with a survey of the work of the Travellers' health visitor, led to interviews with Travellers in a health centre and on caravan sites in Hackney. The initial intention of the interviews was to help explain the findings in the other parts of the study, but they evolved towards a wider understanding of Travellers' views about health and health care.

1.1 Thesis

Locally based research focused on Travellers as an ethnic group and examining their relationship to primary health care professionals reveals areas of unmet need and helps to articulate health care priorities.

My study demonstrates poor access to appropriate health services and its consequences for preventive and screening activity. I also document the continuous pressure of evictions from temporary caravan sites and the poor environmental

conditions in which Travellers in Hackney were forced to live. Although environmental issues transcend health care policy, health care professionals need to address them because of their effects on health. In this study, Travellers themselves prioritised environmental conditions and control of their mobility above health care.

I adopted a range of methods to study Travellers health care including practice-based collection of birth weights and immunisation status in children and cardiovascular risk factors in adults, postal questionnaires to general practitioners and semi-structured interviews with Travellers themselves. The rationale for these methods is discussed in chapter three. In this introduction I want to locate the study in a wider context: the relationship between health status, health care and ethnicity.

1.2 What is an ethnic group?

Ethnicity is a contested category, which provides ample opportunity for political, sociological and anthropological debate (Kahn 1981). In different societies the content of ethnic identity may include language, religion, economic activity, kinship structure, food preparation, clothing and skin colour. But these are by no means universal requirements. There is consensus among social scientists that the concept of ethnicity is meaningful only where groups of different ethnic origin have been brought into interaction within some common social context (Epstein 1978). Ethnicity is then expressed in a system of symbolic and physical boundaries emphasising the differences between one's own and other groups, including and excluding individuals and often reflecting a self-conscious political project (Anthias 1992).

Whichever cultural characteristics demarcate particular ethnicities, an ethnic group is recognised both by its own members and by others (Mares and others 1985). For Epstein (1978) there are two central aspects to ethnicity, one external and "objective", the other internal and "subjective". The external aspect, amenable to classical sociological research methods, is a system of social classification. It provides a set

of categories with ethnic labels in terms of which people structure their environment and govern certain of their relations with others. The internal aspect of ethnicity, which can only be elucidated from within the discourse of the groups involved, is based on identity. *Self-identification* is an integral part of the semantics of ethnic classification.

> ...[T]he meaning of ethnicity cannot be sought out in a purely deductive manner, it requires the cooperation of the people involved...they themselves play the part of theoreticians in this field (Hastrup 1982:158).

Of course, ethnicity is not the only boundary of group identity: class, locality, gender and age may all play this role. All these categories have an objective status, embedded in economic and social realities and a subjective, symbolic quality, which Cohen (1986) maintains may allow simultaneous expression of individual and collective identities. He highlights people's prowess in making ordinary and unremarkable aspects of their behaviour eloquent statements of identity (1986). Of course what appears ordinary and unremarkable behaviour within one group may seem extraordinary in another, which reinforces the symbolic boundary between them.

Although ethnicity is not the only "bounded" group category in our society, it is a powerful identifier because of marked cultural differences between ethnic groups, a frequent association with different skin colour or physiognomy and power differences between ethnic groups expressed as racism and discrimination. Skin colour is sometimes used to define "racial" instead of ethnic groups, partly to highlight the importance of discrimination. In this discussion I follow Cruickshank and Beevers (1989) in using the term "ethnic" instead of "racial", as the latter relates degrees of melanization to non-existent biological or genetic differences.

When discussing ethnicity and health, some authors conflate "ethnic" with "ethnic minority" to refer to any group of people who share a cultural heritage, are not part of a majority and may experience various forms of discrimination (Donovan 1984:663). This incorporation of discrimination *into* the definition of ethnicity may

be misleading, in so far as it overlooks the "ethnicity" or cultural particularity of the majority group. On the other hand, researchers need to be continually reminded about the impact of racism and discrimination when they study ethnicity, health status and health care, as they often gloss over the power relationships between minority ethnic groups and the majority population (Pearson 1986).

1.3. Health research and ethnic minority groups

Research on the health status and health care of ethnic minority groups is a relatively new field (Cruickshank and Beevers 1989, Rathwell and Phillips 1986). The justification for research addressing these health needs has three components:

- Particular ethnic groups may have different patterns of morbidity and mortality from the majority community.
- Membership of an ethnic minority may affect health beliefs and perceptions of illness and health services.
- Health services may be less accessible to ethnic minorities and health professionals may discriminate against them.

As this study focuses health care research on Travellers as an ethnic minority, I need to explore these three rationales.

1.3.1 Different morbidity/mortality

In the United States African-American men suffer an excess mortality from all major causes of death except suicide compared to other groups (Cooper 1986). There is no systematic data on class differences in mortality. Navarro (1990) argues that much of the mortality gap is a result of class not ethnic or racial differences but recent work shows that at each level of income blacks have a higher mortality than whites (Sorlie and others 1992).

National mortality data in the United Kingdom is not coded by race or ethnic identity, but there are studies of standardised mortality ratio (SMR) by country of birth such as Balarajan's (1991) work on ethnic differences in cardiovascular mortality in

England and Wales. Although not necessarily relevant to non-migrants, most data from these studies suggest that influences on mortality cannot simply be ascribed to class (Marmot 1986). For instance, Irish immigrants have a similar social class mortality gradient as the general population, but in each class the SMR is higher; conversely immigrants from Africa and the Caribbean have a *higher* mortality in non-manual than manual classes.

> These figures suggest that the forces determining mortality in immigrants are not well summarised by the conventional social class measure. Either this measure is not completely capturing the social position of the immigrants...or it is not reflecting the environmental and cultural/ethnic influences on disease risks (Marmot 1986:15).

Low social class and poverty remain powerful determinants of illness and premature death for the whole population (Morris 1990). Trying to separate the effect of class from that of ethnic group on mortality or morbidity may be misleading as socio-economic factors which are not "captured" in the class definition may still be central. These may be obscured by focusing on cultural or genetic factors. The latter crop up repeatedly in discussions of ethnic minority health status, as in Carney's statement:

> The higher level of [West Indian and Asian] cardiovascular disease without an association with the known risk factors...seems to be one example of genetic variation (1989:931).

In fact, genetic variation within ethnic groups is much greater than between them (Hill 1989) and is unlikely to explain significant variations in morbidity and mortality. Cooper argues that

> ...explanations based on biological determinism(ie. genetics) exert a grossly disproportionate influence in public health...By the same token the analysis which 'controls for socioeconomic conditions' entirely misses the point about...[ethnicity]; it is or can be construed as a socio-economic category (1986:22).

For example, in addition to generally lower incomes, African-Americans by virtue of their ethnic identity are at greater risk of environmental and occupational hazards. A recent example is a study by the Commission for Racial Justice in the United States which showed that three out of five of the largest commercial hazardous waste landfills are in predominantly African-American or Latino communities. The ethnic

identity of the communities was a better predictor of site location than income or property values (Radford 1992).

With the exception of specific genetic disorders like thalassaemia or sickle cell disease, the illnesses of ethnic minority groups are not intrinsically different from the majority community. These genetic disorders are interesting to doctors, although this does not necessarily result in appropriate preventive services. Donovan (1984) points out that a concentration on these "interesting" diseases or those that might constitute a threat to the majority community, such as tuberculosis, has meant that the opinions of black people about their own health have been largely ignored, as have the obvious links between health and levels of deprivation and racial discrimination experienced by black people in Britain. Death in different ethnic minorities in the United Kingdom is caused by the same range of illnesses found in the majority population, albeit in different proportions: cardiovascular and respiratory diseases and cancer.

1.3.2 Health beliefs

In parallel with the overemphasis on genetic factors in ethnic minority health research there is a tendency to ascribe morbidity differences to health beliefs or dietary practices which are culturally based. A prime example was the initial research and the subsequent campaign around rickets in the South Asian community in the United Kingdom. Donovan (1984) showed that this research mostly blamed individual and cultural choices about diet and clothing, ignoring the potential contribution of social and environmental conditions, particularly poor housing.

An analysis of health beliefs may be helpful to target culturally-appropriate health education and to increase the ability of health care professionals to understand the perspective of their patients. The danger is the attribution of health problems entirely to cultural differences.

> Literature which explains the health problems of ethnic minority communities in terms of cultural factors fosters the misconception that the way of life of those communities is in some way inferior or less adequate than those of the majority, and therefore needs to be changed for 'people's own good' (Mares and others 1985 48).

Health beliefs are not the exclusive preserve of ethnic minorities, but are present within every culture as lay models more or less influenced by the medical model (Helman 1978). These are complex and heterogenous even within what appear to be homogenous social groups. For example, the sample of working class mothers interviewed by Pill and Stott (1982) on a suburban housing estate in Cardiff gave a wide range of responses when asked about the "main reasons for illness". Like the heterogeneity of beliefs within groups, cultural change is another brake on generalising about ethnic minority views and practices. Groups are never static, particularly if they are embedded in a wider majority culture from which different concepts and behaviours are adapted and transformed.

Recognition of lay and ethnic minority health beliefs is incomplete without reference to medical practice, which is both culturally specific and in a specific power relation to other health beliefs (Wright and Treacher 1982). Ethnic minority beliefs are not *intrinsically* problematic nor is the issue simply one of miscommunication or cultural mismatch within a pluralist society where patients meet their doctors on equal ground. The relationship between the medical profession and most patients is unequal, with the medical profession traditionally defining the nature of the patient's presenting problem and determining treatment and more recently searching (screening) for pathology and exhorting the patient to change their lifestyle (Skrabanek 1988). There are norms of behaviour, informed by the white, middle class and male origins of most British doctors which are probably not shared by the majority of people in Britain. Members of ethnic minorities may be even further removed from these behaviourial norms, which doctors may interpret as a "problem" of minority cultures. This critique has direct implications for the research which I undertook with Travellers.

> A major consideration is therefore whether the research findings facilitate and enable the struggle of minorities against oppressive structures and improve their access to health; or whether the findings serve to continue the over-emphasis of culture and the need for superficial tinkering to make 'communication' more effective (Pearson 1986:113).

1.3.3 Health services use

It is difficult to disentangle "voluntary" differential use of health services from problems of access and discrimination. Consultation rates in general practice vary between different ethnic groups, with a trend for increased consultations by patients of South Asian origin - controlling for class differences[1] - and varying results for patients of West Indian origin. (Balarajan and others 1988, Gillam and others 1988). Balarajan and his co-authors state that it is

> ...encouraging to see the degree of access that these communities [West Indian and South Asian] have to primary care, making it feasible for the NHS to take positive initiatives to deal with the specific needs of these communities (1988:960).

Other studies have detected differences in access to general practitioners. For example, Rashid and Jagger (1992) showed from structured interviews with 450 Asian patients and controls that the former more often experienced difficulties in trying to see their general practitioner. Consultation rates are a crude measure of access, partly because they are confounded by differential morbidity but also because they do not necessarily reflect the quality or appropriateness of care. Consultations by ethnic minority patients may be unsatisfactory if, for instance, the general practitioner is less likely to broach preventive issues. Gillam and coworkers' (1988) study of a practice in Northwest London found that "Native"(sic) British patients were more likely to leave the surgery with a follow-up appointment than patients from minority groups. This finding suggests that the quality of primary care for ethnic minority patients may differ from that for patients from the majority community. Anecdotal reports that ethnic minority parents in general made less use of immunisation have not been confirmed by research showing equal or higher use of these services by some groups compared to the majority population (Baker and others 1984). On the other hand the same research shows that other groups have lower rates. The reasons for these differences have not been studied.

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[1] Systematic class differences in access to general practitioners or in quality of care received have been found in some studies but not others. The debate is reviewed in Whitehead (1988).

Studies of consultation rates will not pick up discrimination against ethnic minorities which results either in a complete refusal to register particular groups of patients or selective acceptance. Anecdotal evidence from the West Midlands that some practitioners do not accept black patients was partly confirmed by a study of 2000 inner city households. Practices with which the families were registered showed a sufficient variation in distribution to indicate "the operation of a system leading to racial disadvantage (Johnson 1986:204)". Johnson acknowledges the problems of interpreting this variation and, implicitly, the limits of quantitative methods either in detecting discrimination against ethnic minority patients or in understanding what patients expect from their doctors.

Donovan (1986), using a qualitative interview method with 30 informants of Afro-Caribbean or Asian origin, was able to enquire directly about their views of doctors and health care. There were no direct accounts of discrimination and the complaints about their doctors (waiting time, automatic writing of prescriptions, lack of time) were not expressed in the context of racial discrimination. Cornwell (1984a), with a similar method, has shown that this range of complaints is not specific to ethnic minorities. Most complaints of discrimination practices brought against the NHS have been about employment and personnel issues, rather than delivery of services (Pearson 1989).

Even where the individual health professional does not consciously discriminate against a patient or express overt racism, an ethnocentric approach which does not recognise the validity of other cultures' health beliefs may prevent equitable health care. This form of discrimination can be embedded in medical practice, as in psychiatry where ethnocentrism has been shown to adversely effect the diagnosis and management of patients from ethnic minorities (Burke 1989). Lack of attention to specific needs of minority groups creates another, more subtle, barrier to equitable health care. Fuller and Toon (1988) refer to the "pseudo-egalitarian" approach where all patients are "treated the same" which discriminates against groups who find it difficult to access appropriate services or communicate with health professionals. In this light examples of discrimination include the absence of interpretation or advocacy

services for patients who do not speak English or the absence of women doctors for patients for whom it is forbidden to be examined by a man. This wider definition of discrimination, which includes direct and indirect forms, is the basis of the Commission for Racial Equality's (1992) code of practice for primary health care. This code explicitly addresses the problem of access to health services:

> It is unlawful for those providing primary health care services to discriminate directly or have policies and procedures that are indirectly discriminatory... [so that] persons of one racial group find it disproportionately difficult to obtain access to primary care services (CRE 1992:27).

1.4 Dissertation structure

In this introduction I have discussed the legitimacy of research on ethnic minority health needs, beliefs and primary care provision. I have also highlighted the role of discrimination both in disease aetiology and access to health care for these groups. Chapter Two summarises the historical, ethnographic and political arguments for considering Travellers a distinct ethnic group. I characterise aspects of their legal and social position which are relevant to a study of health care needs and discuss the situation of Travellers in Hackney, where my study was based. I then review the literature on Traveller health status and health care. This leads to specific questions which articulate my general thesis that Travellers in Hackney have unmet health care needs. Chapter Three discusses the methods used in the study, examining each part of the study separately: survey of primary care providers, primary care-based epidemiology and Traveller interviews. Chapter Four presents the results, again separating the three parts of the study. Chapter Five analyzes the results in terms of the specific questions formulated at the end of chapter two, combining data from the different parts of the study. This is followed by a discussion of environmental conditions on caravan sites and Traveller mobility. I conclude by returning to the issue of Traveller ethnicity and health care and discuss future research with Travellers.

CHAPTER TWO: LITERATURE REVIEW

2.1 Traveller-Gypsies in the United Kingdom

Traveller-Gypsies are one of Britain's oldest ethnic minorities (Mayall 1988, Cannon 1989, Vesey-Fitzgerald 1973) but recognition of their health care needs is relatively recent and patchy. Travellers[1] are conspicuously absent from medical textbooks which discuss ethnic factors in disease aetiology and medical practice (see for example Fuller & Toon 1988, Cruickshank & Beevers 1989). This stems partly from a failure to recognise that Travellers are an ethnic minority. In an excellent handbook on multiracial health care (Mares and others 1985), Travellers are missing from the list of ethnic minority communities although, paradoxically, there is a description of a mobile clinic for Traveller-Gypsies in East Anglia. By way of contrast, recognition of Travellers as an ethnic group is not problematic for historians, anthropologists or Travellers themselves. In this chapter I start with a general review of the literature about Travellers as an ethnic minority and move to studies about Traveller health and health care.

2.1.1 Origins

The first authenticated records of Traveller-Gypsies on the British Isles date from 1505 in Scotland and 1514 in London. Their origin is still the subject of ethnographic debate. One theory, expressed romantically by Kenrick and Bakewell, holds that "North West India formed the cradle of the Romany nation (1990:8)." Romany, the main Traveller language in England and mainland Europe, was shown in the 19th century to resemble a form of Sanskrit spoken in North-West India up until 1000 A.D. This observation is used in support of the "diffusionist" theory that English and

[1] Throughout this work I use the term "Traveller", to cover the whole range of traditional Gypsy and Traveller communities. I do not include the more recent group "New Age" Travellers, who are culturally distinct from the Traveller Gypsy population, although they fall into the broad definition of the Caravan Sites Act. I have also adopted the convention agreed by Save the Children Fund (Bagehot A, personal communication) and Traveller organisations of capitalising "Traveller" and "Gypsies" analagous to other ethnic groups.

Welsh (though not Scottish and Irish) Travellers are the descendants of migrants from India who crossed Asia and Europe over several centuries, coming to England and Scotland in the early sixteenth. This theory is challenged by Okely:

> It may be the case that groups of people brought or appropriated some linguistic forms... related to Sanskrit in the movements along the trade routes between East and West, but it does not follow that all 'real' Gypsies or Travellers are the genealogical descendants of specific groups of persons allegedly in India nearly 1000 years ago (1983:12).

Vesey-Fitzgerald (1973) argues that there is good evidence for nomadic communities in the British Isles before the 16th century. Even at the time when the first Gypsies ('Egyptians') were recorded there was a large mobile population of labourers from the breakup of feudal estates. Members of these groups may well have intermarried with groups who identified themselves or were identified as Gypsies. Subsequent intermarriage between Traveller-Gypsies and the settled population is well-documented for at least the past 200 years (Fraser 1992).

The debate around origins is not purely academic. The 19th century Gypsiologists who articulated the Indian origin of Gypsies were steeped in theories of racial purity and identity (Mayall 1988). These theories were the foundation of persistent attempts to differentiate "true" or "pure-blooded" Gypsies from other itinerant groups, whatever the groups' self-identification. The mythical splitting of "real" Gypsies from other Travellers continues to the present day (Acton 1974b). Before the Caravan Sites Act of 1968, central government policy on caravan site provision ignored the needs of the majority of Travellers on spurious racial grounds. Even after the Act's broad definition of Traveller-Gypsies ('Persons of nomadic habit of life whatever their race or origins'), local authorities periodically raise the shibboleth of "real" Travellers to minimise their responsibility for site provision (Okeley 1983). Medical researchers also fall foul of the distinction between "true" and non-Romany gypsies. Williams and Harper, who have carried out genetic studies of Welsh Gypsies write: "Careful distinction must be made...between true gypsies of Romany origin and other itinerant groups (1977:80)." Williams and Harper provide some evidence for genetic affinity between Gypsy and Indian populations but also report considerable heterogeneity in Gypsy communities.

2.1.2 Ethnic Identity

Rejection of a racial theory of Traveller origins should not obscure the cultural distinctiveness and ethnic self-identification of the Travelling population in the British Isles. As with other ethnic minorities, Traveller culture and identity is heterogenous, roughly reflecting national identities of the settled population: English, Welsh, Scottish and Irish.

The largest group, numbering over 70,000, are English and South Welsh Travellers, some of whom speak a creolised dialect of Romany. The Kale of North Wales, numbering less than 500 people, speak an inflected Romany dialect. Scottish Travellers, numbering approximately 17,000 traditionally speak Cant. Irish Travellers, with over 20,000 in the Republic, 1500 in Northern Ireland and 8000 in England still speak Gammer, which combines Shelta with English and Romany (Kenrick and Bakewell 1990, Liegois 1987).

Differences between these groups are often exaggerated, particularly in the attempt to distinguish 'real Gypsies' from others. Okely (1983) argues that, like many other nomadic communities, national identity based on place of birth is much less important to Travellers than to the settled population. In her field work she found significant intermarriage between 'national' groups and a varied discourse around national identity which often depended on the context. For example, in an argument with a local authority officer a Traveller might deny any Irish identity, but would refer to himself as Irish in family discussions.

There are consistent features of Traveller culture and identity which are common to most Travellers wherever they originate in the British Isles and whether or not they live in caravans or houses. Many of these features are common to Gypsies across Europe and in the United States (Kenrick, personal communication). Gypsy and Traveller activists, argue that nomadism is a specific world view which has powerful social, economic and symbolic functions in Traveller life and is central to Traveller ethnic identity, whether settled or mobile.

> The physical fact of moving is just one aspect of a nomadic mind-set that shows in every aspect of our lives. Nomadism entails a way of looking at the world, a different way of seeing things, a different attitude to accommodation, to work and to life in general (McDonagh & McDonagh 1993:33).

The number of Travellers who temporarily or more permanently live in houses is difficult to estimate, but Kenrick and Bakewell (1990) believe that about half of the community live in houses at any one time. For Travellers house dwelling is a function of accommodation, not identity. The proportion of Scottish and Welsh Travellers in houses is higher than other groups, whereas that of Irish Travellers is lower and the English Travellers are equally divided between housed and nomadic families. A prerequisite for recognition as a Traveller by other Travellers is at least one Traveller parent. Central features of all Traveller culture, include resistance to wage labour, multiplicity of occupations, preference for mobility, predilection for caravans and homologous pollution beliefs (Okely 1983). The last feature has a direct bearing on health issues and may illuminate the relationship between Travellers and health professionals which I have explored in this study.

2.1.3 Persecution and discrimination

Discrimination and the history of persecution is central to Traveller life in Britain and the rest of Europe (Puxon 1987). Soon after the first documentation of Gypsies in the early 16th century, the English Parliament passed an Act under which all "Egyptians" in the country were required to leave within 16 days.

> Later legislation introduced the death penalty. The extent to which these laws were applied varied from one part of the country to the other, but men and women were executed in Aylesbury, Durham and York for the crime of 'being a gypsy' (Kenrick and Bakewell 1990:9).

Anti-Gypsy legislation was only gradually repealed after 1783. But, as Mayall points out, persecution of the nomadic way of life by settled society was an important part of new legislation, such as the Vagrancy Act of 1824, which did not distinguish between vagrants and Travellers.

> ...[T]hey were seen as unwelcome and unsavoury parasites. The nomadic way of life stood in defiance to that experienced and suffered by the sedentary population. It rejected materialism, conformity and subjugation to industrial discipline...By the latter decades of the 19th century these rather amorphous and ill-defined antipathetic sentiments were fuelled by mounting evidence concerning illiteracy, sanitation and morality (Mayall 1988:90).

Relations between Travellers and the settled community in the 19th century were marked by evangelical campaigns to convert Travellers not only to Christianity but to a sedentary way of life indistinguishable from the surrounding society. Identification of Travellers as a source of infectious diseases gave further impetus to these campaigns. Nomads have traditionally been seen as a source of illness to the settled community (Haraldson 1979). Even contemporary studies of Traveller health approach it from the position of an actual or theoretical threat to the settled population, presumably reflecting society's fear of Travellers (Hussey 1987). This fear is reflected in medical texts and in acts of violence against Travellers. When there was rumour of a polio case on Thistlebrook caravan site in Southeast London, one Traveller said that "[settled people] thought we all had polio...they used to come down at night with petrol bombs and guns (quoted in Cannon 1989:62)."

Prejudice against Travellers is still widespread and is most vividly seen in areas, such as East London, where there is a significant Traveller population. No other ethnic community has to face such tangible evidence of exclusion as Travellers who read "No Travellers" or "No Travellers No dogs allowed" on the doors and windows of many public houses.

> A lot of pubs put up a sign that says "No Travellers"... It gets you when you're walking down the street and see that written there. You're written off just because you're a Traveller (Power 1988).

Local papers frequently run stories with vicious stereotypes of Travellers (Kenrick and Bakewell 1990) and there are regular reports of violence against Travellers in every part of the United Kingdom, including firebombings and shootings. Periodically demands for the extermination of Gypsy-Travellers find their way into print, such as this statement from a tenant's association report reproduced in the *Essex Post:* "There

is no solution to the Gypsy problem short of mass murder." (24 November 1969:3) Some local politicians, such as the mayor of Dartford, also target Gypsies; in one speech he was quoted as saying that "...they should be pushed over the white cliffs of Dover (Acton 1990:13)."

Individual discrimination and attacks on Travellers are part of a wider institutional discrimination centred around caravan site provision. As my study showed that the shortage of secure, environmentally safe sites is the central health concern of Travellers themselves and corresponds to the importance of housing in public health (Townsend and others 1988), I need to review the argument over site provision.

2.1.4. Site provision

Up until the Caravan Sites Act of 1960, Travellers were able to own small plots of land as sites for their caravans and those of their relations, without planning permission. The new legislation resulted in a halt to the construction of new sites, as planning permission was rarely granted and led to the gradual reduction of site numbers as councils compulsorily purchased land and moved Travellers off (Acton 1974a). Private landlords were stopped from providing pitches as they could not get a site licence. Consequently more and more families were driven onto the roadside (Kenrick and Bakewell 1990). The 1959 Highways Act which made it an offence for a Traveller (but no other group) in a caravan to camp on a highway, was used to constantly move Travellers on. This often resulted in more conspicuous concentrations of Travellers on common or waste land, where they had no security of tenure or basic facilities.

The 1968 Caravan Sites Act, which came into force in 1970, marked a change in government policy towards Travellers. It acknowledged for the first time the nomadic identity of at least some Travellers and required local authorities to provide official sites for Gypsies "residing in and resorting" to their areas. But it also allowed local authorities to apply for "designation" if they provided a number of pitches deemed adequate by the Department of Environment (Acton 1974a). Designation made it a criminal offence for Travellers to station their caravans in a local authority other than

on an official site, even if this had no pitches available. Designation has been compared by Gypsy spokespeople and their supporters to the Pass Laws and Apartheid in South Africa (Kenrick and Bakewell 1990:34).

Twenty five years after the Act came into force over a third of Travellers nationally cannot find a place on authorised sites (Department of Environment census January 1993). This figure is probably an underestimate of illegally sited caravans as local authorities, who provide the figures, have a strong disincentive not to report unofficial sites, as it highlights local underprovision. There is no time limit for adequate site provision and individuals cannot seek enforcement through the courts. Moreover the criteria for designation are ambiguous, allowing local authorities to achieve this status with minimal or, in the case of London authorities, no provision. There is an intrinsic conflict between the essentially nomadic lifestyle of many Travellers, who are not based in one local authority or even one region, and the concepts of settled planners and policy makers, which are premised on place of origin or residence and want to demarcate "local" Travellers.

A Department of Environment review of the operation of the 1968 Act (Wibberley 1986) identified a number of reasons for the shortfall of sites, most notably strong local opposition from the settled community but also unwieldy consultation and planning procedures. Wibberley also commented on the inadequacy of some official sites and potential environmental health risks. During the election campaign of 1992 the Conservatives coupled strong anti-Traveller rhetoric with promises to change the 1968 Act. After their re-election, their consultation paper proposed removal of central capital funding of local authority caravan sites, increased powers to evict Travellers from illegal sites and reinstated the pre-1968 policy of encouraging Travellers to abandon a nomadic lifestyle (Department of Environment 1992).

2.1.5 Boundaries

The Travellers' beleaguered position in the midst of the settled population is central to the development of pollution beliefs. These are part of a coherent system of

symbolic boundaries distinguishing Travellers from the majority population ('Gorgios'[1]) and balancing the ever-present threat of assimilation into the dominant society.

> The problem is how to remain separate and different, while maintaining daily contact with Gorgios, to whom Gypsies must present many disguises. All roles, whether trickster, exotic or victim, carry the risk of self-degradation and a dangerous sense of unreality, unless the 'inner self' is protected intact...Group integrity must be expressed in some independent way (Okely 1983:77).

Pollution beliefs are a means of sustaining group integrity. They have a real social function and are not a reflection of exotic origins on which gypsiologists traditionally place so much emphasis. Travellers have strong views about purity and cleanliness, with most of the emphasis on the *inner body,* extending to the inside of the caravan, but not to the caravan site itself. Great care is taken with food preparation, so that it does not have contact with body products, to the extent that bowls used for washing hands may not be used for washing food. Gorgio disregard for these distinctions confirms their dirtiness and polluting nature. This may lead to conflict with health professionals, as Okely recounts an incident described from a Traveller perspective:

> A Gorgio health visitor discovered that a Traveller had a deep cut in his foot. Well versed in Gorgio germ theory, she grabbed the first bowl she saw inside the trailer - the washing up bowl - poured in disinfectant and water and bathed the man's foot in it. Afterwards the Travellers threw away the bowl and recounted the incident with disgust (1983:81).

This type of *faux pas* on the part of settled people is not considered accidental by Travellers. The failure of Gorgios to observe inner-outer body distinctions reinforces the ethnic boundary between them and Travellers. The relationship between Travellers and Gorgios constantly threatens the purity of the Traveller 'inner self' which Okely characterises as the focus of their ethnic identity. This is most obvious in the realm of food, for which Travellers are totally dependent on Gorgios, but which is potentially polluting as it is taken into the body. This perceived vulnerability may be

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[1] Irish Travellers use the term "buffers" or "country people" for the settled population.

expressed as a fear not only of being poisoned by food prepared by Gorgios but by health care interventions such as immunisations. Health care facilities are considered threatening, polluting environments, although they are appropriate for certain events which are also polluting, such as birth and death. These distinctions may be important in the planning of Traveller health care.

2.1.6 Travellers in Hackney

Hackney is an inner-London borough where Travellers have stopped for centuries. There is documentary evidence of stopping places and more permanent camps in Hackney Wick, Homerton, Lamb's Lane and Hackney Marshes in the early 19th century (Mayall 1988). London and the surrounding districts were the "undisputed heart of the travelling population" (Mayall 1988:34) in the 19th century and remain an important focus of Traveller life today. Up until April 1993 there were no official caravan sites in Hackney and only one "tolerated site" containing a dozen pitches. Most Travellers in Hackney temporarily stop on waste ground or car parks until the local authority or a private landlord obtains a court order to move them on. The local authority had committed itself to building two sites in 1980. One has just been completed in a desolate industrial area with no local shops, schools or health services. The local police have not had recourse to the Public Order Act 1986, as has been the case in other parts of the country. Nevertheless, until recently, most of the Travellers in Hackney were under continuous threat of eviction.

Estimating a local Traveller population is a difficult exercise (Green 1991), undertaken biennially by each local authority. It is restricted to a count of Travellers' caravans in a district, which automatically excludes Travellers who are temporarily or permanently living in houses. In the period of my study (July 1987 - November 1990) the official caravan count fluctuated between 50 and 70, giving a range of 250-350 individual Travellers in Hackney at any one time. This calculation uses a mean of 5 people per caravan which is an estimate based on visiting caravans over several years. The census data only provides caravan numbers. The Hackney caravan count is probably an under-estimate, which has implications for health service planning, but even if it were accurate I cannot calculate the total number of Travellers living

in Hackney during the study because of movement to and from other London boroughs and other parts of the country, notably the Midlands and Essex.

The majority of Travellers in Hackney identify themselves as Irish, although most of their children are born in England. There are also several Scottish families. The men are largely involved in tarmacking, scrap metal, demolition or site clearance. Most of the women do not have paid employment. Some families receive social security benefits. Virtually all primary age children from the "tolerated site" attend local schools when places are available. Most children from temporary sites and secondary age children do not attend school, although this is partly mitigated by peripatetic teachers for Travellers. In June 1992 less than half of the school age Traveller children living in Hackney were attending school (Traveller Education Team, personal communication).

There is intermarriage between Irish and English Travellers and many similarities in their cultural practices. To an even greater extent than English Travellers, Irish Travellers have had to argue for recognition as a distinct ethnic minority (ITM News 1991). Recent research on the origins of Irish Travellers has rejected the previously widespread notion that they are a recently formed group without an ethnic identity dating from the Potato famine or Cromwell's Irish campaign. In fact records of "Tinkers" date back to the 11th century and Irish Travellers fulfil many criteria for ethnicity, including their own language (Shelta) which probably dates back to the sixteenth century. Three hypotheses have been put forward on their origins: a pre-celtic group marginalised by the Celtic invasion of Ireland; descendants of one of the distinct celtic groups; indigenous nomadic craftsmen who never settled, gradually evolving a nomadic culture (Ni Shuineir, personal communication).

Irish Travellers in England are not a recent phenomenon. There is unambiguous evidence of Tinker families crossing the Irish Sea from at least the early 19th century intermarrying with English Gypsies (Adams and others 1975). Acton (1974a) noted that nomadic craftsmen from Ireland were present in England from at least the reign of Henry V who passed a law to restrain them. More recently, their increasing

economic distress in Ireland with the decline of traditional trades caused increased migration to England in the 1950's and 1960's and there has been a net "emigration" since then. This coincided with the large reduction in suitable sites discussed above. Local authorities appear even more reluctant to provide sites for Travellers of Irish origin than they are for other Travellers and there are repeated reports of police harassment (Power 1988).

There is debate about the economic status of Irish Travellers in England, with some evidence that as a group they are poorer than English Travellers, although Adams and her co-authors claim that this impression masks a "wider range of economic status than among the English." (1975:185) There is no controversy over the fact that Irish Travellers face double discrimination in England (Gmelch 1986) and are scapegoated both by settled people and, occasionally, by some English Travellers (Acton 1974a).

2.2 Traveller health and health care research

There are approximately 1,000,000 gypsies in Western Europe, (including the United Kingdom) 2.5 million in eastern Europe and 500,000 in the USA (Liegois 1987). Yet there is little research into their health status and health care either in the United Kingdom or elsewhere. This is partly the result of some health authorities and funding bodies judging that research on Travellers' needs is not justified. In the "Year of the Child" a survey of all Regional Health Authorities an (unspecified) number stated that Traveller-Gypsy children did not

> ...constitute a large enough problem within the category of 'disadvantaged' to merit arrangements for special research and provision of services particularly for them (Sampson and Stockford 1979:4).

Even if funding is available, access to the Traveller community is often difficult and longitudinal studies almost impossible in such a highly mobile community. In the United Kingdom there is no national mortality data for Travellers because they do not constitute an occupational category, but mortality data is available from Ireland.

When I started my study there were two retrospective surveys of maternal and child health (including mortality) in English counties, several small studies of specific health problems and a number of anecdotal reports from doctors or health visitors working with Travellers. Below I review the literature in English, although I have also included relevant German, French and Hungarian studies, using my own or colleagues' translations. I was unable to translate Polish and Czech articles, although where an English abstract was available and the article was relevant, I cited it. For papers published after 1976, Medline was a starting point in the literature search. Kennington's (1990) bibliography was also helpful. Where relevant I have calculated confidence intervals for some studies and obtained unpublished data.

2.2.1 Maternal and Perinatal Health

One of the earliest reports of serious perinatal problems came from a general practitioner and health visitor in Sheffield. (Heller and Peck 1983). They recorded a cluster of six perinatal deaths out of twelve births to Traveller women between January and August 1982, which led to the appointment of a specialist health visitor for Travellers and the provision of a mobile clinic.

Systematic data on maternal and perinatal health were first collected in an East Anglian study sponsored by Save the Children Fund (Linthwaite 1983) in which 265 Traveller mothers were interviewed about their obstetric history, children's health and use of health services. Using similar questions Pahl and Vaile (1986) reported on interviews with 263 Traveller women in Kent. A third survey which reported on perinatal mortality was the Irish Travellers' health status study (Barry and others 1989) based on prospective reporting of all Traveller births and deaths in 1987 by community care study teams. I have tabulated these results (Table 2.1) and included the perinatal mortality rate from a retrospective study in Marseille of obstetric outcome in 1571 Gypsy women (Adrai and others 1985).

Table 2.1 Summary of Traveller foetal and infant mortality
(rates per 1000 total or live births)

Source	Area	Births	perinatal mortality	still b rths	infant mortality
TRAVELLERS					
Linthwaite 1981	East Anglia	239	142.4	113.9	53.8
Pahl & Vaile 1984	Kent	814	16.0	12.0	17.5
Pahl & Vaile 1984	Kent [under 30 years]	298	22.2	18.5	26.4
Barry & others 1987	Ireland	554	28.3	19.5	18.1
Adrai & others 1985	Marseille	1571	20	not available	not available
TOTAL POPULATION					
OPCS	England and Wales 1981	all births	11.8	6.6	11.1
OPCS	England and Wales 1980 [Social Class V]	all births	18.7	9.6	16.7
Barry and others1987	Ireland	all births	9.9	6.9	7.4

The article reporting the French study also reveals prejudices medical researchers can hold about Gypsies. For example, in their discussion of methods they write:

> Sur le plan psychologique la douleur domine chez cette population aussi bien superstiteuse que croyante (Adrai and others 1985:679). {Psychologically [during labour] pain is the dominant feature in this population which is as superstitious as it is religious}

The appalling mortality figures found in the East Anglian study may partly result from sampling bias. The aim was to sample Travellers within one Regional Health Authority, but this was carried out non-randomly "including as many Traveller families as possible in the survey". There are no details of subject or site selection

method except that

> ...as far as possible a cross-section of Traveller families by type of site and by county within the region would be sampled in comparison with the rest of the population (Linthwaite 1983:3).

From comparison of numbers interviewed with the county censuses of Traveller numbers, the researcher calculated that the survey represented only 42% of the total Traveller families in East Anglia. In an attempt to improve on Linthwaite's methodology, the researchers in Kent (Pahl & Vaile 1986) aimed for interviews on *all* known Traveller sites and with all mothers with children under the age of 15. The survey finally represented 57% (263/459) of total Traveller families in Kent but actually collected information on *more* children than the census number. The methodology of the Irish study (Barry and others 1989) was the most reliable, with mortality returns made by public health nurses on piloted data forms to community care study teams.

Even if one discounts the extreme East Anglian results, the stillbirth rate for Travellers is higher than Social Class V in England and Wales and the perinatal and infant mortality rates for Travellers in both Ireland and Kent are substantially higher than the national averages. Irish mortality data is not stratified by class, but the authors of the Travellers' health status study use stratified mortality data from England and Wales to suggest that Irish Traveller mortality rates are not simply a function of low social class. The subgroup of Travellers in Kent under 30 years of age have increased perinatal and infant mortality and stillbirth rates compared to the total Traveller group interviewed. Pahl and Vaile (1986) suspect that this may be due to poorer recall of their obstetric experience by older Traveller women or increased reluctance to communicate it to the interviewer. Another explanation is that these represent real differences, which is supported by evidence that class differences in post-neonatal mortality are greater among young mothers under the age of 25 (Townsend and Davidson 1982).

The reasons for increased Traveller perinatal and infant mortality rates compared to the whole population are not clear, as the underlying causes of perinatal and infant

mortality are generally not well understood. The East Anglian study showed that the average time of booking for the women they interviewed was 18 weeks and the authors quote studies correlating time of initial contact and perinatal mortality. It would be a mistake though to infer a causal link and overrate the role of antenatal care in preventing perinatal mortality (Hall and others 1980). The Black Report, in discussing underlying causes of perinatal and infant mortality concludes that

> ...none of the results quoted enables us to deal with the question of the relative importance of inequalities in provision or utilisation of health services on one hand and other forms of inequality [socio-economic] on the other in determining inequalities in outcome (Townsend and others 1988:102).

The most powerful predictor of death in the first month of life is low birth weight which is more common in babies born into lower occupational class families (Whitehead 1988). Recent work has confirmed that the effect of social class on neonatal mortality varies with birth weight (Leon 1991), although it is more likely that birthweight is a marker of risk rather than a factor which can be influenced by intervention (Garner and others 1992). Birthweight may also influence adult health; for example, Barker and his team (1993) found that low birthweight correlates with premature cardiovascular deaths. The East Anglia and Kent studies of Travellers determined the mean birthweight and (in Kent) the proportion of low birth weight babies (<2.5 kgs).

Table 2.2 Birthweight of Traveller children

Source	Area	Low birth weight (<2.5 kgs)	Mean birth weight (kgs)
Linthwaite 1983	East Anglia	-	3.05
Vaile & Pahl 1986	Kent	12.8%	-
Adrai and others 1985	Marseille	15%	3.1
England & Wales 1984	all births	6.9%	3.25

The proportion of low birth weight babies is probably more meaningful than the mean weight, as the latter may be biased upwards by the higher birth weight of children born to women of greater parity. This information was not reported in Linthwaite's study and the raw data were no longer available. In Kent Traveller mothers had an average of 3.1 children each, in East Anglia 3.75 and in Ireland 5.3. The range of family size in these studies was one to thirteen children.

Pahl and Vaile (1986) found an increased proportion of reported low birth weight babies among Travellers in Kent, compared to the national figure. They also found that stillbirth and infant death rates were higher for mothers on private and unauthorised sites than on local authority sites (risk ratio = 1.48 for still births but wide confidence interval: .918 to 2.4) and among women who were more mobile (risk ratio: 1.38, confidence interval: 0.615 to 3.11). Aside from the problem of sample size, which make these results tentative, one cannot conclude that unauthorised and private sites or increased mobility *per se* are a cause of an increased still birth rate. They may reflect confounding factors, such as income, nutrition or the inheritance of lethal disorders from increased consanguinity (Williams & Harper 1977), which impact on obstetric outcome.

2.2.2 Child Health

The age structure of the Traveller-Gypsy population throughout Europe differs from the settled population in that approximately 50% of Travellers are under 16 years of age (Liegois 1987). The age pyramid of the Traveller population is similar to that of a developing country: a wide base with many children and young adults with relatively fewer in the older age groups. Child care has a high priority in Traveller culture, not only among women (Franklin and others 1993), but there is evidence for increased child morbidity which authors have ascribed to poor environmental conditions and restricted access to health care.

Sampson and Stockford (1979) noted an increased rate of polio and less serious infectious diseases, as well as an increased accident rate among Traveller children. They did not present any data which support these conclusions. Pahl and Vaile (1986)

showed that 11% of under-five year old Traveller children in Kent were reported by their mothers to have suffered serious injuries, most commonly lacerations, scalds and burns. Their data on serious illness is difficult to interpret because uniform criteria were not used for judging the severity of illness episodes.

In the Kent study mothers reported mental and/or physical handicap in three percent of the children, which is a similar rate to the settled population, although we do not know what criteria the researchers used to define these conditions. In the East Anglia study (Linthwaite 1983) five percent of children were reported to have a "disability (congenital malformation)", which the researcher compares to a 1.6% rate in England and Wales.

Congenital abnormalities may be a particular problem for Travellers because of increased consanguinity (between third cousins or closer). In a study of Welsh gypsies, Williams and Harper (1977) found 43/99 consanguineous marriages, including 14 between first-cousins giving a coefficient of consanguinity of 0.017. Remarkably, the same figure was derived for a Gypsy population in Boston, USA (Thomas and others 1987) and Czechoslovakia (cited by Lescisinova and others 1989). Williams and Harper found a phenylketoneuria (PKU) rate of 1/40 in their sample, compared with 1/16,000 in Wales as a whole. A high rate of PKU was also found in a large study of Hungarian gypsies (Tauszik and others 1989). Williams and Harper identified two other disorders showing autosomal recessive inheritance: two siblings with metachromatic leucodystrophy showing progressive neurological deterioration and two with congenital nystagmus. The authors gave no details of sampling method, so the relevance of their findings to the whole population of Welsh gypsies or other Travellers is difficult to assess.

As with other research on Traveller-Gypsies, it is dangerous to generalise findings, especially when generalisations fit traditional pre-conceptions which settled people have about Travellers. Although medical researchers in Wales, Boston and Slovakia have found a high level of consanguineous marriages, Okely (1983) in her study of 100 Gypsy-Traveller families in the South-East of England found specific prohibitions

against first and second cousin marriages. Her discussion of the uncertain status of genealogical information from her informants casts some doubt on the apparently unambiguous data obtained in medical studies.

On the other hand, the Irish Travellers' health status study (Barry and others 1989) supports the impression that inherited disorders are more common in the Traveller community. Although the numbers are small, coverage of all Traveller deaths was exhaustive. The study found an increased mortality from congenital anomalies in Traveller boys and metabolic disease in boys and girls (see Table 2.6), although this only made a small contribution to total child mortality. In a *Medline* bibliographic search from 1976 to mid-1992 on the health and health care of Traveller-Gypsies I found that more than a third (38/101) of the articles focused on genetic disorders or markers in gypsy populations. This is analogous to medical researchers' over-emphasis on genetic disorders in other ethnic minorities which I discussed in chapter one. The obsession with genetic and biological differences between ethnic groups has a long history and the "allure of genetic explanations" is also strongly evident in behaviourial and psychiatric research (Alper & Natowicz 1992).

There are no data on the developmental assessment of Traveller children, other than growth. In Ireland, a prospective study of 97 children aged between 2 and 13 years showed a consistent height and weight deficit compared with children from the settled community (Creedon and others 1975). Most strikingly, 49% of the boys were below the third centile for height and 31% of the girls below the third centile for weight. However, no conclusion about environmental or genetic contributions could be drawn, especially as parental height was not measured. The sample size also limited any conclusions. The authors did not give standard deviations for the mean height and weights in each age/sex band, so I cannot calculate confidence intervals, but the largest number of Traveller children in one band is twelve.

A retrospective Irish study of 92 Traveller children showed decreased head circumference in the first year of life when plotted on centile charts (Carroll and others 1974). The study was of infants admitted to hospital and the absence of a

hospital-based control group of settled children prevents any conclusion about the difference between these children and others who were hospitalised. The authors were concerned that the smaller head circumferences may reflect retarded brain growth, although the connection they drew between hypothetical "recurrent intestinal and respiratory infections" and poor nutrition in these children is, at best, speculative. They intended to study their later intellectual development, but have not published any further results. The same study showed age appropriate length and weight in these children. There is no comparable data from the UK, but these studies may be relevant to Traveller children in the United Kingdom because of the relatively large influx of Irish Travellers over the last 20 years. Most of the Travellers in Hackney are of Irish origin.

In the range of child health problems which have been reported in Traveller children, non-accidental injury has not been noted. In a study in Walsall, where environmental and physical risk factors were increased for Traveller children, compared with settled children, there was a *lower* incidence of non-accidental injury in the Traveller community (Crout 1988).

2.2.3 Immunisation

In 1979 Sampson and Stockford observed a low level of immunisation among Traveller children and an increased rate of polio and less serious infectious diseases. Several studies of child health subsequently highlighted low immunisation rates (Table 2.3). I have not found any studies of Gypsy immunisation rates in Western Europe to compare with British data. Nor are there any published reports from Eastern Europe on *Medline* searching back to 1974, despite its large Gypsy population. One report from the United States of a measles outbreak (originating from exposure to a boy with measles at a Gypsy wedding in Montana) points out that none of the 17 infected children had been immunised, but gives no further information about Gypsy immunisation rates (Dales and others 1983).

Table 2.3 Four studies of Traveller child immunisation rates (children vaccinated by end of second year as a % of total born compared with figures for all children in England and Wales)

Source	Area	Number	Polio	D/Tet	Perts	Meas
Linthwaite 1983	East Anglia	226	7	9	0	12
Vaile & Pahl 1986	Kent	216	24	24	10	14
Crout 1988	Walsall	not available	20	20	5	12
Mckenzie 1990	Bradford	20	25-30	25-30	15	75
DHSS 1986	England & Wales	all DHA's	84	84	65	62

I have already questioned the overall validity of the East Anglian study (Linthwaite 1983). With respect to immunisation status, the others have a number of methodological limitations. First, they are based almost exclusively on parental reports of immunisation status and no attempt was made to validate the reports from other sources, such as manual or computerised records at district level or records held by health visitors and doctors. Second, either no information is given about sampling methods and size (Crout 1987) or the sample was very small and restricted to clinic attenders (Mckenzie 1990 and Mckenzie, personal communication) or in an attempt to study the whole population there were intrinsic difficulties in assessing the response rate (Pahl and Vaile 1986). Third, the two large studies in East Anglia and Kent cannot be generalised to non-rural areas where almost a quarter of Travellers live (Streetly 1990).

The effect of these low immunisation rates is difficult to assess. Pahl and Vaile (1986) state that epidemics of infectious disease have not been reported among Travellers and speculate whether this is due to poor reporting of episodes (unlikely in the case of polio, diphtheria and tetanus) or to the relative isolation of Traveller communities. A Scottish study suggests an alternative explanation: that despite low immunisation rates a high proportion of Travellers are immune to polio and tetanus (Bell and others 1983, Riding 1985). In a sample of 109 Travellers aged five to 61 years the reported

immunisation rate was low: 56% had no recollection of any immunisations. However 84% had all three polio antibodies, 49.5% tetanus antibodies and 9% protective levels of diphtheria antitoxin. The polio and tetanus immunity levels are similar to the settled population. The explanation for the relatively high polio immunity is probably the circulation of poliovirus (wild or vaccine-derived) in the Traveller community sufficient to elicit an antibody response in a large proportion of Travellers. Evidence for faeco-oral transmission comes from the high proportion of Travellers with antibodies to Hepatitis A (94%) in this study. Despite the reassuring polio immunity levels, there is some evidence for a substantially increased risk to Travellers. There were 70 cases of paralytic poliomyelitis in England and Wales between 1970 and 1984; in 19 a wild virus was isolated. Four of these were in Traveller families, giving a crude odds ratio of 143 (95% c.i. 47 to 434) between Travellers and the population as a whole for paralytic poliomyelitis from the wild virus (Begg and others 1987). A 1978 outbreak of paralytic polio in France with 25 cases included 18 Travellers (Poliomyelitis surveillance 1979).

High tetanus immunity in the Scottish study may reflect opportunistic immunisations in accident and emergency departments after injuries, although the level is probably still insufficient in the light of common Traveller occupations: farm work, scrap metal, tarmacking, fly tipping. Diphtheria immunity reflects childhood immunisation; the low rate compared with the general population (65%) indicates poor integration into immunisation services. Both diphtheria and polio immunity were lower on unofficial than on official sites. Sampling was biased towards official sites (65% of the sample) with toilet facilities and running water, where only a minority of Travellers live.

Previous studies of immunisation among Travellers have speculated about the cause of the low uptake, suggesting a combination of poor access to services and parental attitude:

> We were told that some mothers regard it as dangerous. On one hand this may reflect the debate about brain damage after whooping cough immunisation. On the other hand, it may derive from the traditional Traveller culture in which the inside of the body is defined as 'clean', while anything outside it is dirty. Seen from this point of view immunisation constitutes putting something which may be dirty into the clean body (Pahl and Vaile 1988:210).

Okely quotes the Gypsy writer Boswell who recalls: "our people had always been against vaccination" and who, when conscripted and faced with immunisations said "I will not be poisoned." (1983:84) The fear of poisoning from immunisation has recently been recorded among Bulgarian Gypsies in the context of preventive health care (Rich 1991), where a poliomyelitis epidemic has led to a mass re-immunisation campaign. This is actively resisted by Gypsies because of rumours that the treatment was intended not to immunise but sterilise their children. This terminal threat to ethnic identity was a reality in Nazi Europe, where many Gypsy women were sterilised and at least one third were murdered (Kenrick and Puxon 1972). The recent recrudescence of violence against Gypsies in Germany and Eastern Europe (Hancock 1991), extending to pogroms in Roumania (Stephen 1992) is taking place less than 50 years after the Gypsy Holocaust (the *Porajmos*).

There has been no published research on Travellers' views of immunisation; what information we have about their perspective is anecdotal. The contribution of parental views to the reported low immunisation rates is uncertain. This is not the case for the settled population, in which study of a large, randomly selected sample of parents and health professionals showed that parental attitude is the major cause of non-immunisation, particularly with respect to measles and pertussis (Peckham and others 1989). The strongest influence on vaccine uptake was attitude to the safety of pertussis vaccine. Lower social class, the presence of older siblings and of chronically ill children in the family were also strongly associated with lower uptake.

There has been no assessment of initiatives to immunise Traveller children, but one report allows a guarded optimism about targeted interventions. Lewis (1982) reports immunising 92% of a Traveller community on a large unofficial site after members has expressed anxiety about the risks of polio after an unvaccinated baby on another

site developed paralytic poliomyelitis. Lewis gives credit for the high vaccine uptake to the Romany Guild representatives who visited the site two days before the team of three doctors and two nurses. Surely another element in this success was the fact that Travellers themselves prioritised immunisation because of first hand information about the dangers of polio. The success, unfortunately was only partial; on the day when the first dose was given, an eviction order on the site was already pending. Three weeks later, before the second course was due "the [G]ypsies had gone".

2.2.4 Adult health

There is anecdotal evidence from Walsall (Crout 1988) and Sheffield (Wilson 1987) that premature death from cardiovascular disease is more prevalent among Travellers than in the local settled population, even when this is predominantly working class. Traveller health projects have also noted, but not counted, widespread smoking among adults (Crout 1987). Heller and Peck (1983) noted a high incidence of respiratory tract infection, along with chronic skin conditions and ear, nose and throat and eye problems. They do not state the prevalence of each condition or analyze the age distribution. Although there is no reliable adult morbidity data for Traveller Gypsies in the UK, a study of 58 American Gypsies, showed alarming rates of chronic disease and cardiovascular risk factors (Tables 2.4 and 2.5). The study had severe limitations because of the sampling method:

> Eleven patients were seen early in the study [in a general medical clinic]...we screened 36 other gypsies from the Boston area; they were approached at Gypsy's death feasts and saints' days...Data on an additional 11 subjects, recently deceased family members and other local Gypsies, were obtained from review of medical records and family interviews (Thomas and others 1987:377).

The strong bias in this sample towards patients presenting for general medical care means the results do not represent the community prevalence of these disorders. Nor can we assume that this group of Traveller patients are more ill than a comparable group of clinic attenders from the settled population, since there were no controls. Nevertheless, the frequency of cardiovascular and metabolic disease was disturbing. Thomas and his colleagues found a high degree of consanguinity in this group of Gypsies and postulate an important role for heredity in the high prevalence of disease.

Table 2.4: Prevalence of chronic disease and cardiovascular risk factors in 58 American Gypsies (Thomas and others 1987)

Risk factor or disease	Number	Percentage
Hypertension	41 56	73
Type II Diabetes	24 52	46
Hypercholesterolaemia (>6.5 mmol/l)	26/39	35
Periph vasc disease	20/51	39
smoking	49/57	86
obesity (>20% over ideal BMI)	49/58	84

Table 2.5 Stratification by age of cardiovascular risk factors in 58 American Gypsies (Calculated from raw data provided by Thomas).

Cardiovascular risk factor	AGE			
	<30	30-39	40-49	50+
Type II Diabetes	8%	17%	56%	82%
Hypertension	43%	67%	100%	79%
Hypercholesterolaemia	20%	56%	43%	50%

To date there are no studies of Traveller cardiovascular risk in the UK, so we do not know if these results are relevant here. American gypsies are certainly related to European Traveller-gypsies, most arriving in the USA in the late nineteenth and twentieth centuries. Many aspects of their lifestyle and culture are similar to those of British Travellers (Thomas 1985).

As "Traveller" or "Gypsy" are not occupational categories, OPCS mortality statistics do not identify Traveller deaths. Nor have there been any studies of Traveller mortality in the UK. Mortality data is available from Ireland from a study which I have already mentioned in the context of perinatal deaths (Barry and others 1989). Information was collected on the cause of 84 deaths as recorded on death certificates or as determined by the community care study team in the area where death occurred.

Table 2.6: Irish Traveller mortality 1987

	Standardised mortality ratio (95% confidence intervals)		
	Men	Women	All
All causes	222*(163-296)	307*(217-421)	254*(202-314)
Natural causes	192*(133-169)	227*(175-289)	227*(175-289)
Accidents	397*(205-694)	612*(225-1333)	450*(267-711)
Cancer	117 (38-274)	242*(105-478)	172 (92-294)
Metabolic (1-14 years)	1250 (32-6965)	2000 (51-11143)	1538*(186-5557)
Cardiovascular	168 (89-296)	217 (99-412)	185*(116-280)
Respiratory	233 (63-595)	720*(329-1367)	438*(233-748)
Genitourinary	417 (11-2322)	1000*(121-3612)	682*(141-1993)
Congenital anomalies	727*(198-1862)	0 (0-586)	339(92-868)

* significant at 0.05 level

The disparity between total mortality rates for Travellers and the rest of the population becomes clear when one considers the social class differentials for mortality in the UK. The SMR for social class IV and V males is 141 and for married women is 135 (Townsend and others 1988). Even taking into account the relatively small sample and hence the wide confidence limits on Traveller mortality rates, these results show a substantially greater differential between Travellers and the settled population in Ireland than the largest differential in the UK. It is likely, from similarities between Travellers' physical and socio-economic circumstances in the UK and Ireland, that a similar differential mortality exists in the UK.

Perhaps surprisingly, in the light of the American study, the increased SMR for Traveller cardiovascular disease in Ireland is overshadowed by the increased mortality from respiratory and genitourinary disease, particularly in women. Thomas and his colleagues (1987) found relatively little respiratory compared with cardiovascular disease, which was one of their arguments for a substantial hereditary contribution

to cardiovascular pathology in their sample. Methodologically, the Irish study was more reliable and more likely to reflect the true prevalence of life threatening diseases. Another explanation for the discrepancy is that, despite similarities, the two populations (Traveller gypsies in Boston USA and Irish Travellers) had different patterns of morbidity and mortality.

Both studies concluded that Traveller men and women had a reduced life expectancy compared to the rest of the population. Thomas and his colleagues (1987) noted 14 deaths at a mean age of 48 and the "local gypsy leaders" thought the average lifespan was 55 years. Barry's study (Barry and others 1989) found an average life expectancy of 61.7 for men and 65.3 for women, a deficit of 9.9 years for men and 11.9 years for women, compared to the settled Irish population.

2.2.5 Environmental Health

Although some of the studies cited above suggest a hereditary component in the raised morbidity of Travellers, there is consensus among health professionals concerned with Travellers' health that the main explanation lies in adverse environmental conditions and poverty.

> The environment in which many Travellers live is not one which is conducive to good health...many, perhaps even the majority of sites both legal and illegal, represent some kind of health hazards for Travellers and their families (Cornwell 1984b:9).

I have already discussed the national shortage of official caravan sites, forcing at least one third of Traveller families to camp illegally. Unfortunately, even when a Traveller family is on an official local authority site, there is no guarantee of a safe environment. A study carried out by Kent housing officers in 1984 showed six official sites on former refuse tips or adjacent to active tips (unpublished report quoted by Pahl & Vaile 1986). A survey of the official Westway site in West London demonstrated dangerous airborne and soil lead levels (Strehow 1980). Pahl and Vaile (1986) found that basic amenities were absent on many sites in Kent, including official ones. The provision of basic amenities in East Anglia (Linthwaite 1983) was even worse (Table 2.7). Hyman (1989) interviewed 88 Travellers on authorised and

unauthorised sites in 5 London boroughs (Brent, Haringey, Enfield, Harrow and Newham) about environmental facilities; although the results were expressed in a different form, they are comparable to the Kent and East Anglia data.

Table 2.7 Three studies of basic amenities on Traveller caravan sites (percentages)

Source	Area [TOTAL NO.]	Water	Toilets#	Rubbish collect	Post	Electric
Linth-waite 1983	East Anglia [265 families]	70	42	65	not asked	not asked
Pahl & Vaile 1986	Kent (authorised*) [158 families]	64	29	41	55	59
Pahl & Vaile 1986	Kent (unauthorised+) [104 families]	1	9	4	22	10
Hyman 1989	London [54 families] (authorised)	0	0	0	50	37
Hyman 1989	London [34 families] (unauthorised)	29	29	29	0	0

* including local authority and private sites
+ including tolerated sites, road sides, waste land and fields
# including chemical toilets

While even authorised sites may not have basic environmental amenities, conditions on unauthorised sites are comparable to shanty towns in the developing world. In Kent about 60% of Traveller mothers interviewed study reported problems caring for their children because of

> ...dirt, fast traffic, rats, lack of safe play areas, difficulty drying clothes, overcrowding, mud, dogs, broken glass, the site getting 'used up' with toilet holes, lack of education, noises from factories, smells from nearby sewage works (Pahl and Vaile 1986:20).

A consideration of environmental conditions needs to go beyond the physical environment. In chapter one I have already discussed harassment of Travellers by settled people and the underprovision of sites, resulting in the perpetual threat of eviction for at least a third of Traveller families. This creates intolerable psychosocial pressures on many Travellers, which result in their acceptance of "tolerated" or authorised temporary sites even if environmental conditions are poor.

Poverty is also a problem for Travellers, partly because traditional economic niches have disappeared but also as a result of evictions and lack of site security. This coupled with the second recession in the UK in ten years has lowered Traveller income. Women Travellers are increasingly "trailer-bound" and an increasing proportion of men are dependent on social security (Crout 1987). Not all Travellers are affected in this way; as in the settled population there is a polarisation between the relatively well off and the poor (McCarthy, personal communication).

2.2.6 Access to health care

Health care is not necessarily a major determinant of health status, but

> ...inequality in the availability and use of health services in relation to need is in itself socially unjust and requires alleviation (Townsend and Davidson 1982:27).

There is some evidence that poor access to primary health care is a major problem for Travellers. One study suggests that many general practitioners do not accept Travellers as patients. Linthwaite (1983) found that 27/45 general practitioners in East Anglia who responded to a questionnaire did not accept Travellers on their lists. This result is difficult to interpret because the sample was non-random and there is no information on the characteristics of responders and non-responders. It is also not clear whether the responding general practitioners would see Travellers as temporary residents. Most anecdotal accounts of Travellers' health care mention general practitioner hostility towards these patients (Sampson 1982, Streetly 1987, Montague 1987). This is highlighted in a conference report on Travellers' health care:

> Not all doctors will accept Travellers on their lists and there were numerous reports at the conference of Travellers being turned away, often in a rude and harsh way, from doctors' surgeries...[as a result] many Travellers, in common with others who have experienced rejection by professionals, are understandably reluctant to make contact with the health service at an early stage... (Cornwell 1984b:12).

As a consequence, Travellers may often travel great distances to attend general practitioners who are sympathetic. Pahl and Vaile (1986) found that 19% of their sample had a general practitioner more than five miles away and five percent travelled more than 20 miles. In the Kent study 85% of Travellers said they were

registered with a general practitioner. Interviews with Travellers in North East London found an 81% registration rate (96% on authorised sites, 56% on unauthorised sites), although not necessarily in the same borough. "Registration" was self-designated in these studies and did not necessarily correspond with permanent registration on a general practice list as opposed to temporary registration.

General practitioners are not alone in turning Travellers away. Travellers' health visitors also report hostility from health professionals in antenatal and child health clinics (Sampson 1982). Discrimination against Travellers directly contravenes the Race Relations Act, but even if all general practitioners and clinics welcomed Travellers, there might remain other barriers to good health care: the mobility of Travellers, different cultural perceptions of illness and time keeping, non-literacy, absence of postal services and the absence of medical records.

Enforced mobility, when Travellers are evicted from unauthorised sites, means appointments are difficult to keep and it is particularly unlikely that non-urgent conditions will be treated if there is a waiting list. The provision of antenatal and postnatal care is also undermined (Durward 1990). In a survey of Association of Metropolitan Authorities members 43/67 authorities responded to a question about provision for Traveller families. 16/43 said they would evict pregnant women and 13/43 said they would evict women close to birth from unofficial sites. 15/43 said they would evict mothers with new born babies (Patel 1988).

As I discussed previously, Traveller culture contains specific health beliefs, which may be at greater variance with the prevailing medical model than the health beliefs of the settled population. This complicates consultations with health professionals and, combined with frequent moves, means that a relationship with a doctor or nurse is less likely to develop (Cornwell 1984b). This deprives Traveller parents of the opportunity to take health education ideas into account when making decisions about the health care of their children and compromises the prevention of adult illnesses.

Non-literacy is still widespread in the Traveller community both in the UK and throughout Europe. Liegois (1987), quoting an unpublished report by Acton and Kenrick, estimates that 85% of Travellers are non-literate in England and Wales (70% under the age of 30). In Ireland, almost 90% of Travellers are thought to be illiterate, although no literacy data has been collected. Most young adult Travellers would prefer to be literate and are concerned that their children do not have continuous access to primary education, because of enforced mobility (Kenrick & Bakewell 1990, MacAongusa 1993). The absence of postal services, particularly on unofficial sites, diminishes access to outpatient and investigative services because appointments cannot be sent out to Travellers on these sites. Furthermore, recall systems for preventive and screening services in primary care depend on a postal address.

The mobility of Travellers, enforced or voluntary, results in patients often being seen by general practitioners and hospital doctors without medical records. If a Traveller family is registered with a general practitioner, moves and is able to re-register, the records may take several months to catch up with them. If they are a very mobile family, they may well have moved on by then. If a family is temporarily registered with a general practitioner (unless special provision is made within the practice) notes will be sent to the Family Health Service Authority every 3 months with the temporary resident claim form, even if the family is still living in the area. Problems with continuity of care and lack of medical records prompted the Sheffield Travellers' mobile clinic to produce a hand-held family medical record card. Other Traveller health projects in Kent, West Midlands and East Anglia have also introduced record cards (Durward 1990). The use of these records has not been studied. There are anecdotal reports that initial enthusiasm has been dampened because many general practitioners are not aware of their existence and do not request them from their Traveller patients (Pahl and Vaile 1988).

2.2.7 Health authority policy

Barriers to health care require action on the part of health authorities to plan services and actively seek out Traveller Gypsies, especially those who are on unofficial or temporary sites. In an early analysis of health care for Travellers, Sampson and

Stockford (1973) wrote to all regional health authorities in England for information on their services for Traveller families. All 14 replied and many passed on the request for information to area health authorities. In all information came from two thirds of the 90 authorities. Although a few authorities tried to plan services for Travellers, had initiated multi-disciplinary teams and even provided mobile health clinics, the majority did not make any provision for either permanent or non-permanent caravan sites. Travellers on non-permanent sites are least likely to be registered with a general practitioner and the survey concludes that

> ...with one exception the only health care services roadside families receive were as a result of a chance encounter (the possibility of a health visitor popping in) or as the result of an accident or other emergency admission to hospital (Sampson and Stockford 1973:3).

Seven years later, in a questionnaire to directors of community nursing services in all English district health authorities (87% response), Hussey (1988) found that the situation had not improved. Only 11 districts had any kind of outreach or special maternity facilities for Travellers, although 50 had a designated person with responsibility for Travellers' health care. Of the 158 districts with a general policy on prevention or health promotion, only five mentioned Travellers. Hussey concluded

> ... that there is little intersectoral collaboration and planning; that there are many problems with the delivery of preventive health care and that some districts know little about Travellers and campsites in their areas (1987:53).

Since the NHS Act, which came into force in April 1990, purchasers and providers are split, with each district acting as a purchaser authority on behalf of its local population. Funding to districts is on a capitation basis, weighted to reflect the health and age distribution of the "resident populations" (Department of Health 1989). I have already discussed the difficulties of counting Travellers, only a minority of whom will be "resident" in an area. The Department of Health has not yet specified how they are to be included in evaluation of the local population.

2.2.8 Travellers' health visitors

Although the national picture of health care for Travellers is one of patchy provision, there are a growing number of specialist health visitors and health projects concerned with the health of Travellers. While Travellers' health visitors are sometimes part of a mobile team including a community medical officer (Streetly 1987), they often work in relative isolation. The nursing literature contains vivid accounts of their work although there has been little assessment of the range of tasks they undertake or their effectiveness. The approach of these professionals was initially an adaption of the traditional health visitor role focusing on preventive health care of young children with an agenda of health education for mothers (McCann 1987). Often this was not successful:

> I sometimes feel that I have lost my way as a health visitor, as the last thing a young gypsy mother wants to hear about is preventive medicine or health education. She wants help getting the smashed window replaced in her trailer and sufficient money to buy food for her family and for her washing at the launderette. Above all, she would like a stopping place for the trailer, without fear of harassment from the local residents or local authority (Peck 1983:365).

An important development in Traveller health care is the adoption of a patient centred approach (Crout 1988, Lawrie 1983) starting from the Travellers' concerns and problems. This considerably broadens the role of Travellers' health visitors, who become advocates mediating between their clients and health professionals, local authority staff, social security officers and police officers. Travellers' health visitors work in different ways, as documented in the Maternity Alliance's collection of reports on various Travellers' health projects (Durward 1990). The projects display a variety of solutions to the problems health care access and poor communication between health, welfare and educational agencies. The West Midlands project is inter-professional, with health education and welfare workers part of one team, whereas the Sheffield project only has health workers. All prioritise integration of Travellers into main stream health services, although many use mobile clinics to bring specific services onto caravan sites. In an area with a significant Traveller community the role of the Travellers' health visitor, if one exists, needs to be examined in the context of Travellers' health care needs and other primary health care agencies.

2.3 Health and health care in Hackney

The East London borough of Hackney, with a population of about 190,000 people, is one of the poorest in UK, with most of the classic features of the inner city environment: low quality housing, high unemployment and high population mobility. With Tower Hamlets it has the highest proportion of overcrowded households, households with no car, single parent families and children in care (Harrison 1983). The borough has a higher proportion of social class IV and V residents than any other district in the UK and a significant homeless population (City and Hackney Health Authority 1991). The City and East London family health service authority, which also includes Tower Hamlets and Newham, has the highest Jarman index in England (City and East London Family Health Services 1992). More than a quarter of the population is estimated to belong to one of a wide range of ethnic minorities, including West Indians, Africans, Turks and South Asians (OPCS 1991). A recent study estimates that 10% of the Hackney population consists of refugees (Jacobsen 1992). Standardised mortality ratios in Hackney are among the highest in the country for children (129) and young adults (141) mostly as a result of socio-economic deprivation, although an under-estimate of younger residents might artefactually inflate the ratios (City and Hackney Health Authority 1992). Morbidity from tuberculosis, mental illness and asthma, is higher than and uptake of childhood immunisation and cervical smears is lower than other areas (City and Hackney Health Authority 1991). Like other inner London areas, Hackney has a high turnover of population.

There are 124 principal family doctors practising from 60 sites in the City and Hackney area. Despite efforts by the local Family Health Service, the majority of practices are in poor quality and cramped premises (City and East London FHS 1992). Most practitioners are single-handed or practising with one other principal. There are two adult accident and emergency departments in the district at St. Bartholomew's and Homerton hospitals. The majority of children residing in Hackney are seen in the accident and emergency department at Queen Elizabeth Hospital for Children on the Tower Hamlets/Hackney border.

2.4. Research questions

The most surprising aspect of this literature review is how rarely Traveller health and health care was studied. In order to provide an empirical basis for improving primary health care for Travellers in Hackney, I chose to reproduce some of the research discussed above, albeit with different methodologies. I prioritised preventive issues which are considered important in primary health care.

CHILD HEALTH

1. Is there any difference in birthweight between Travellers and the local settled population or evidence for poor child growth?
2. Is there any difference between immunisation rates of Travellers in contact with primary care services and the local settled population? If there are, what are the reasons?

ADULT HEALTH

3. Is the cardiovascular risk status of adult Travellers attending general practice different from the local settled population?
4. Is the prevalence of alcohol abuse among adult Travellers attending general practice different from the local settled population?
5. Is the cervical smear rate for Traveller women attending general practice different from the local settled population? If it is, why?

HEALTH BELIEFS

6. Is it possible to explore Traveller health beliefs through semi-structured interviews? What are their views on illness prevention?

PRIMARY HEALTH CARE

7. Do Travellers have problems gaining access to primary care services in East London? Are general practitioners excluding Traveller patients? What problems do practices face in providing health care for Travellers?

8. What is the role of the local Travellers' health visitor? What problems does she face and how is she regarded by Travellers?

9. Will hand-held medical records be used by Travellers?

Most of these questions were addressed by more than one research method. To avoid repetition I have structured the methods and results chapters by the three main methods I adopted: surveys of health care providers, descriptive epidemiology, and interviews. The structure of the analysis chapter (sections 5.2 - 5.5) is based on the nine research questions, bringing together data from the different methods

CHAPTER THREE: METHODS

3.1 Overview

The study of Traveller Gypsy health and health care is problematic. I have already discussed the limitations of previous studies. Travellers' mobility makes longitudinal studies difficult and ignorance of their demography makes it impossible to accurately define a denominator for community-based surveys. Their low literacy rate makes written questionnaires inappropriate. The overt racism which Travellers are exposed to on a daily basis and the rejection which they may have faced at the hands of health care providers makes many Travellers suspicious of settled people and, in some cases, health workers.

The paucity of information about Travellers' health status and health care in an inner city area led me to a broad-based study using a number of different research tools, rather than an in-depth study of one health issue. The different parts of the study can be seen as a search for appropriate methods with which to analyze the preventive health care needs of this group. My approach to Travellers' health and health care is eclectic, with methods adapted from epidemiology and social science and applied within a primary care context. Eclecticism is an accepted feature of primary care research (Norton and others 1991), although this study had an additional constraint in that it dealt with a marginalised community.

It was important to choose study methods which were acceptable to this community and I aimed to consult Travellers themselves on proposed methods, if not overall aims. Consultation was not straight forward. I sent the research protocols to four national Traveller organisations. Two (The Association of Gypsy Organisations and the Advisory Committee for the Education of Romany and other Travellers) replied with supportive comments and a few suggestions. But these organisations do not necessarily represent the views of Travellers in East London and were no substitute for local consultation. Even locally there were uncertainties: those Travellers who I had come to know were inevitably those who were easier to consult, but in crucial

ways were not representative of Travellers in Hackney. For instance, the Travellers I consulted early on in the study either attended general practice regularly or were active in the Hackney Travellers' support group. Nevertheless, methodological choices were influenced by consultation. I indicate below modifications to methods arising out of discussion with Travellers.

Another intrinsic problem of Traveller research, at least in Hackney, is the relatively small population present in the borough at any one time. Basic health data was collected in primary care settings, to capitalise on a context where Travellers were anyway having to provide health-related information and avoiding the logistic challenge of sampling on temporary caravan sites for the epidemiological part of the study. Therefore this part of the study is largely a description of general practice **attenders**, and cannot be generalised with any confidence to the whole Traveller community in Hackney or nationally. Some correction for this bias in the case of children came from collection of data in an accident & emergency department as well as general practices. The problem of sampling bias is discussed further in chapter five. The small population of Travellers in Hackney at any one time meant that the epidemiological arm of the study had to run for 18 months to collect a reasonable sample. I depended on the forbearance of general practitioners and accident and emergency nurses who collected the data. This may explain the less than complete recruitment of Travellers presenting for primary care and some missing data.

I agree with the Maternity Alliance that in Travellers' research

> ...it is appropriate to identify needs and there is no necessity to show that Travellers are unhealthier than the rest of the population to justify essential services which should be theirs by right...(Durward 1990:15).

Why then did I choose to collect epidemiological data on a control sample of settled people? Hackney has a deprived population with high morbidity. Although comparisons between Travellers and the settled population may not be necessary to justify "essential" services for Travellers, a demonstration of relatively increased need helps practices and health authorities (with fixed budgets) to prioritise intervention and the targeting of additional services. The data I collected about the control group

is available from national surveys (eg. blood pressure, serum cholesterol) and in the case of certain variables (eg. immunisation and cervical smear status) specifically from Hackney. But if one accepts the rationale for comparing data from the Traveller and the settled community, the method of collection should be the same, necessitating a matched control group. Moreover, in the case of local data, inaccurate family practitioner committee (now family health service authority) registers and incomplete reporting made immunisation and cervical smear rates unreliable (Beardow and others 1989).

The study had three parts:

Survey of primary care providers: A questionnaire was sent to all general practitioners and community medical officers in Hackney and Tower Hamlets to determine views towards Traveller patients and to locate practices who saw large numbers of Travellers with a view to using them for epidemiological data collection. The general practitioner and community medical officer survey was complemented by a review of the work of the specialist health visitor for Travellers in the North East Thames Regional Health Authority.

Primary care-based epidemiological survey: Data was collected from consecutive Traveller adults and children presenting to two general practices and a children's accident and emergency department. Hand-held medical record cards were issued to these patients.

Interviews with Traveller adults took place on Hackney caravan sites and one practice waiting area.

Prior ethical approval was obtained from the City and Hackney Health Authority ethical committee for the epidemiological data collection (including blood specimens) and interviews with Travellers.

3.2 Survey of primary health care providers

3.2.1 Questionnaire to general practitioners and community medical officers

In June 1988, a short questionnaire (appendix A) was sent with a covering letter to the senior partner of every practice in Tower Hamlets and Hackney. He or she was asked to complete the questionnaire or pass it on to one of their colleagues where appropriate. A similar questionnaire was sent to all community medical officers running child health clinics in Hackney. The questionnaire was first piloted in three practices outside East London and several questions were slightly modified to eliminate ambiguity. I only requested one completed questionnaire per practice. Non-responders were sent one repeat questionnaire. If no response was forthcoming the practice was rung and the questionnaire administered to the senior partner by telephone, if this was acceptable.

I requested answers to questions 3-9 (2-8 in the case of child health clinics) only if a Traveller patient had attended the practice or clinic in the past 12 months. Responses to each question on the questionnaire were converted into proportions/percentages. There was space on the back of questionnaire for additional comments. The need to identify practices who treated significant numbers of Travellers for the data collection phase of the study precluded anonymous questionnaires.

3.2.2 Review of Traveller health visitor's work

The aim of the review was to characterise the role of the specialist Travellers' health visitor (THV), undertake a quantitative and qualitative assessment of her workload and make recommendations for how the role could evolve.

Discussion with post-holder: the range of work undertaken by the THV was reviewed in several round-table discussions between members of the study team and the post holder.

Three-month retrospective survey: analysis of weekly returns (Bloomsbury health

visitor format) July-September 1987, with comparison to returns of four Bloomsbury health visitors. The Bloomsbury format was altered (Appendix B) so that details of work specific to a Travellers' health visitor could be recorded: number of caravan sites visited, number of caravans/site, referrals to dentist, welfare advice and assisting Travellers to use general practice surgeries. Each health visitor's weekly returns were added up and an average weekly workload for each category of task was calculated.

Two week prospective survey: The data collection categories in the retrospective survey were too general to provide a clear picture of the THV's role, although it had the advantage of a relatively long study period. One of my collaborators (Joan Miller) spent a working day with the THV from which we designed a log for the post holder to complete at the end of each day for more detailed information about her work. The log recorded information in the following categories: demography of caravan sites visited, morbidity of patients seen, preventive health care undertaken, development work and liaison carried out and comments about problems encountered and unmet needs (see appendix C).

3.3 Descriptive epidemiology

3.3.1 Recruitment centres

Seven practices in East London reported seeing at least one Traveller patient per week. After discussion, five felt unable to accommodate the research project because they were concerned about the extra work involved. This left two practices in Hackney where data collection was possible. Discussions with the consultant in charge of the accident and emergency department of the local children's hospital, Queen Elizabeth Hospital for Children (QEH) suggested heavy use of this department by Traveller families, making it an appropriate third recruitment centre. Data was collected between July 1988 and September 1989 at Queen Elizabeth Hospital and between September 1988 and February 1990 in the practices.

Both practices had six partners and one trainee with practice populations ranging between 10,000 and 11,000 patients during the period of data collection. One practice

was based in a health centre, the other in its own premises. Both had well-defined catchment areas but shared a policy of accepting Travellers as patients wherever they were living. The majority were registered as temporary residents. Neither practice used computers for patient data, other than registration details. Both practices ran child health clinics and had two to three attached health visitors. Queen Elizabeth Hospital is located on the borders of Hackney and Tower Hamlets. The accident and emergency department has approximately 26,000 attendances per year of which 47% come from the City and Hackney health authority (North East Thames Regional Health Authority 1993).

3.3.2 Recruitment criteria

Traveller cases were defined as patients presenting to QEH accident and emergency department or to the two general practices fulfilling one of these criteria:

- a caravan site as place of residence
- a previous caravan site address in the notes
- known to be part of a Traveller family by receptionists or nurses

Although this method of identifying Travellers may seem haphazard, any "false positives" could be detected when the doctor or nurse asked permission of the patient or their parent to take part in a study of Travellers' health. Travellers new to the area who lived in houses were excluded. This was probably a small number since Travellers newly arrived in Hackney usually spent a considerable amount of time on caravan sites before moving into a house (McCarthy, personal communication).

I met with the receptionists in the practices and the nurses at QEH accident and emergency department to discuss the recruitment criteria and requested that they recruit all Traveller patients who fulfilled the criteria who presented in the study period. These patients had a data card (Appendix D) attached to their notes by receptionists or nurses. This card was then filled in by the general practitioners in the practices and the by the nurses in the accident and emergency department.

In the practices controls from the settled population were selected by identification of two sex-matched patients with birth dates nearest to each index (Traveller) patient

using the practice age/sex registers. A data card with the same format as that used for the Traveller sample was fixed to the cover of the notes. Doctors were asked to fill in the cards at the next consultation. In the accident and emergency department, after recruitment of a Traveller child, nurses were asked to enter the next two (non-Traveller) patients into the study. Recruitment of age-sex matched controls was not possible in this department.

I requested recruitment of consecutive Traveller patients presenting within the study period. In QEH the proportion of Traveller children recruited was estimated by periodic examination of the Accident and Emergency registration book, where the names, addresses and dates of birth of all children presenting to the department are recorded. The names in the book were matched with the record of children recruited into the study. Traveller children can be accurately identified from caravan site addresses. In the case of Traveller children living in houses, they can be roughly identified from key names of Traveller families, although this will over-estimate the proportion of unrecruited children since it includes Travellers who did not fulfil the recruitment criteria and a small number of non-Traveller children who had typical Traveller names. In the practices, the notes of *all* Traveller patients seen during the study period were kept in a separate box and at the end of the study the names and dates of birth of these patients were compared to the record of children recruited into the study.

Once Travellers (or controls) were recruited in the practices, their notes were labelled to prevent double recruitment. At QEH, data cards were kept in a box in the accident and emergency department to prevent the same child being recruited twice. If Travellers were recruited in two centres, only data from the second centre was used in the analysis.

3.3.2 Data collection

The choice of variables was based on the questions about Traveller health and health care posed at the end of chapter two (p.57), taking into consideration the limited time

for data collection in a single general practice or accident and emergency department consultation. To increase the likelihood of continued cooperation of the twelve general practitioners and dozens of paediatric nurses who filled in the data cards, the information I requested was limited to that which would be directly useful to these health professionals. The cards for adults (> 15years) were different for men and women (appendix D). Each card had a unique number code. Two variables (height and weight) were collected at QEH, but not the practices .

Practices

Children: birthweight, immunisation status

Men: blood pressure, smoking (cigarettes/day), alcohol consumption (units/week), random serum cholesterol, random serum glucose, polio antibodies

Women: blood pressure, smoking, alcohol consumption, date of last cervical smear, random serum cholesterol, random serum glucose, polio antibodies

Queen Elizabeth Hospital

Name of general practitioner, birthweight, immunisation status, height, weight

Points about specific variables

I only included children aged under six years in the analysis of **immunisation status** because parental recall becomes progressively less reliable the older the child and secular trends in immunisation uptake (eg. increase in pertussis uptake in the 1980's) would undermine conclusions based on too wide an age range of children. The larger sample size from inclusion of the older children was not necessary to detect important differences between Traveller and settled children. Although immunisation status was recorded for infants, I excluded children under one year old in the analysis. At the time of the study City and Hackney health authority was using the three/six/nine month schedule of triple antigen+polio administration. In April 1989 the measles/mumps/rubella (MMR) vaccine replaced measles and data on both vaccines are coded together. Information was not collected on pre-school boosters.

Information about stated **address** was collected for each patient from the temporary patient registration card (FP19) or notes folder in the practices and the accident and emergency registration book at QEH. Information about address and type of residence

at the time of consultation was not necessarily reliable. The local Travellers' health visitor noted that some Travellers who used to stay in Hackney but had moved to Haringey still used Hackney practices and gave the address of a Hackney caravan site (Dodge, personal communication). Practices colluded in this misinformation since they would not be paid for a temporary patient if they lived in another Family Health Service area. Travellers who were temporarily squatting in a house may have given a caravan site address and Travellers who were registered from a house may have continued to give this as their address if they have moved into a caravan, for fear of losing their registration.

General practitioners were asked to record the average of two **blood pressure** readings using the sphygmomanometers ordinarily available to them. I demonstrated a method of measurement recommended by the British Hypertension Society (Petrie and others 1986) to each doctor participating in the study.

Blood samples from adults for **cholesterol, glucose and polio antibody** estimation were taken by the doctor who collected data from the Traveller or control patient (adults only). When the patient presented to reception, the receptionist was asked to attach a plastic bag to the data card The bag contained partly completed investigation request forms, syringe, needle and blood bottles to facilitate venepuncture. I asked doctors to explain the blood tests and the nature of the study to patients and controls and to request permission for a specimen to be taken.

Two bottles were then delivered by the routine transport service to the Homerton Hospital where the specimens were split up: the fluorinated specimen was sent to the chemical pathology laboratory at the Homerton Hospital and the clotted specimen was transported by van to another processing point at St. Bartholomew's Hospital, from where it was sent to the Lipid laboratory. After spinning it down and using the serum for a random cholesterol analysis, the remaining serum was sent onto the virology laboratory in the same hospital for polio antibody analysis. I did not have the resources to arrange special transport of the specimens or to ensure that copies of the results were sent directly to me. The results were retrieved from the notes of

Traveller and control patients whose names were on the database. If results were missing, the appropriate lab was contacted and if they still were not available a request was inserted in the notes to repeat the test if the patient presented again in the course of the study.

Data processing

The data cards were piloted in one practice and at Queen Elizabeth Hospital and slightly modified. I had periodic meetings with some of the doctors and nurses participating in the study to discuss further problems with the design of the cards and data collection. After patients were seen and the cards were completed (or not) by the doctors they were placed into a special box in both practices and Queen Elizabeth. When a Traveller patient presented, the box was checked to ensure that he had not already entered the study. If data were accidentally collected twice on the same patient, only information from the second consultation was recorded. When information was missing from a data card, a note was appended to the data card requesting completion at the next consultation, if it happened in the time scale of the study. The data were copied manually from the cards and then entered into a database (SPSS/PC Version 3.0). Validity checks were carried out at data entry and data cleaning functions were used.

Two-tailed statistical tests were used throughout, *t* tests for comparison of means and the chi-square test for comparison of proportions using SPSS (SPSS/PC+ Version 3.0) software. Confidence intervals were calculated by the confidence interval analysis computer program (Version 1.0). Statistical significance was taken as $p < 0.05$. Concordance between parental recall of immunisation status and written records was tested by calculation of a kappa statistic for each type of immunisation and application of the McNemar test (see p.70).

Hand-held medical record cards

Hand-held record cards are used in a number of Traveller health projects but have never been evaluated. I designed a hand-held folder with inserted cards for each

family member (appendix E). I consulted four local Traveller families and two Traveller organisations about the design and use of the folder and cards. Attached by a perforated edge to each individual insert was a "response card", with a message to the doctor or health visitor who was next consulted by the patient after the card was issued. This health worker was requested to complete the card and post it back to the project. The two objections from Travellers I consulted were the inclusion of women's health details in the family card and details of the specific patient on the response card. The final version of the card incorporated these points. At the start of the study posters about the Travellers' hand-held record were displayed in four local accident and emergency departments, reminding doctors and nurses to request the card from Traveller patients. I also publicised use of the card to general practitioners through a national weekly medical magazine.

Women's health details: several Traveller women were concerned that information about contraception and cervical smears would be seen by their husbands or children and would therefore no longer be confidential. They said they would not give permission for this information to be included in a family record, but would be happy to use a separate women's health record.

Response card details: the two Traveller organisations were concerned - from a civil liberties perspective - that no information about individual patients should be included on the response card that was sent back to our project once a patient had been seen. Therefore the response card only included the address of the health professional sending it, a question about whether it had been useful to them and identification of the patient as a man, woman or child.

Reporting bias and validation of immunisation results

One problem about collecting smoking, alcohol cervical smear and immunisation data directly from patients in the context of primary care is a tendency for patients to want to present a favourable picture to the doctor or nurse. Therefore smoking and alcohol rates may be lowered and immunisation and smear rates raised. If these biases were equally shared by Traveller and control patients, differences between the groups

would not be effected. Unfortunately one cannot assume equal bias.

In the case of immunisations I attempted a full validation exercise, consulting the district immunisation data base and manual records. Several sources of recorded data on immunisation were checked in an attempt to validate parental recall. These were the City and Hackney immunisation database, manual practice-based child health clinic records and records kept by the Travellers' health visitor (for Travellers only). If two different records of immunisation were available for a child, I chose the one that contained the most recent information to compare to parental recall.

A kappa statistic was calculated for Travellers and controls in both the practices and the accident and emergency departments to provide a measure of the level of agreement between parental reports and other methods. The range (0 - 1) can be interpreted as follows - <0.4: poor to fair agreement; 0.4 - 0.6: moderate, 0.6 - 0.8: substantial; 0.8 - 1: almost perfect. I also assessed whether there was a bias towards 'over-reporting' from parental or other sources with the McNemar test. Neither the kappa statistic nor the McNemar test assume that the parental or the other reports are correct, but provide an index of agreement or disagreement (Mckinney and others 1991).

I did not attempt this exercise with cervical smear results, but partly addressed the uncertainty about recollection of the exact year of a woman's last smear by analyzing this data on an "ever/never" basis.

3.3.4 Sample size

Taking into account the results of other studies, I calculated the number of children and adults I needed to recruit to detect differences between Travellers and controls for a number of variables which I considered particularly important for the planning of primary health care intervention: immunisations, birthweight, current weight, cervical smears, smoking, hypertension and diabetes. Power considerations were not the only rationale for choosing variables, although they were important in excluding a number of health problems (eg. congenital abnormalities or abnormal obstetric

outcome) which have such a low background prevalence that I would have had no chance of detecting a meaningful difference even on the most optimistic recruitment assumptions.

Analyzed categorical or binary outcome variables (ie. complete/incomplete immunisations; $<2.5/\geq 2.5$ kgs birth weight, ever/never had a cervical smear and smokers/non-smokers) I calculated the standardised difference for each variable:

$$\frac{p_1 - p_2}{\sqrt{\bar{p}(1-\bar{p})}}$$

where p_1 and p_2 are proportional outcomes in the control and Traveller samples and $\bar{p} = (p_1 - p_2)/2$. With the standardised difference one can use a nomogram to determine the sample sizes required for a specific probability (85% in these calculations) of detecting such differences significant at the 5% level (Altman 1991).

Immunisations: From the study of immunisation rate in Kent (Pahl&Vaile 1986), where the highest completion rate was for the primary polio course ($<30\%$), the number of children required to detect this difference in completion rate in Hackney between Traveller and control children (completion rate of 80% in 1989) was only 36 (18 Travellers and 18 Controls). The power requirement to test the Kent findings in Hackney was trivial and with the number of children ultimately recruited, smaller differences could be detected.

Birthweight: The Kent study showed almost a doubling of the proportion of low birth weight babies (<2500 g) among Travellers compared to the regional figure. To detect a similar increase in Hackney, where the background rate was 9.1% I would have needed to collect birth weight information on 500 children (250 Travellers and 250 controls). At the start of the study this seemed to be achievable, as between the practices and QEH, approximately 300 Traveller children were seen annually. As the study progressed, smaller absolute numbers of Travellers in Hackney and incomplete recruitment resulted in a smaller sample size, reducing the power of the study to

detect important differences in birthweight between Travellers and the settled community.

Current weight: In a study of school children Creedon and others (1975) found that 49% of Traveller boys and 31% of Traveller girls had weights below the third centile level. To detect 30% of Traveller children below the third centile I would have needed a total sample of 65 children which seemed a feasible target for recruitment at the QEH accident and emergency department (the practices did not agree to measure weight).

Cervical smears: There were no previous studies of cervical smear uptake by Travellers on which to base a power calculation.

Hypertension: The study by Thomas and others (1987) in Boston Massachussetts is the only source from which I could estimate the possible difference in proportions of hypertensive patients from the Traveller and settled community. In a general medical clinic population they detected a prevalence of 78%, which partly reflects their choice of 90mm Hg as a threshold for diagnosis. The background prevalence of hypertension varies with its definition, age and the context in which data is collected. Tudor-Hart's (1987) estimate of prevalence in general practice attenders greater than 15 years of age is six per cent. To detect the difference between this level and that observed in Boston, only 12 Travellers and their controls would need to be recruited. At the other extreme, to detect a simple doubling of the background rate from six to 12% would require 400 Travellers. It seemed feasible to recruit 100 adult Travellers, only allowing the detection of a difference between Travellers and the settled population if the Traveller rate was as high as 30%. Therefore, although I could test Thomas' findings of an "epidemic" of hypertension among Travellers, with this sample size I could miss important differences.

Diabetes: I was able to test the high level of diabetes detected by Thomas (48% against a background prevalence of two) with a very small number of Travellers: 12. But to detect a doubling of background rate would have required 2200 patients.

3.4 Interviews with Travellers

My aim in this part of the study was partly to clarify issues emerging from the epidemiological data collected in the two practices and QEH accident and emergency department (ie. low immunisation and cervical smear rates), but also to give voice to Travellers' own views about health and health care. Marshall and Rossman (1989) argues that qualitative studies are particularly appropriate for

> ...research that seeks to explore where and why policy and practice do not work and for which relevant variables have yet to be identified. (1989:46).

Unstructured tape-recorded interviews with three Travellers were conducted on one caravan site. These were analyzed and formed the basis of a semi-structured questionnaire, which was piloted with two Travellers. Their responses were tape-recorded and the questions reassessed. The questionnaire was then extensively rewritten and piloted with six more Travellers and slightly modified. The results of these six interviews are included in the data I present below. The main areas of the questionnaire were: mobility, illness aetiology, use of health services, use of hand-held medical records, immunisations, women's health care, environmental facilities, smoking, alcohol and literacy.

In discussion with Travellers before interviews began I learned that some Travellers preferred to be interviewed on their caravan site and others preferred to be interviewed in a practice. Therefore the questionnaire was administered to adult Travellers on the three largest sites in Hackney and in the waiting area of one of the practices in which Traveller data was collected in the epidemiological part of the study. On the sites, after knocking on a caravan door or meeting Travellers outside the research assistant introduced herself as a researcher collecting information on Travellers' health care. She requested an interview about their views of health care in Hackney. She assured the potential respondents that their answers to questions would be reported anonymously. The respondent's name and date of birth was recorded on the first page of the questionnaire which was then separated from the rest of the questionnaire, with all pages retaining a unique numerical identifier.The

interviews lasted 25 minutes to one hour and were often interrupted, especially if several people were present, when it tended to evolve into a group discussion. The interviewer noted the answers of the main respondent. Where two respondents were interviewed together, the answers were noted separately. During interview sessions in the practice the interviewer approached all adult Travellers while they were waiting to see a doctor. She said the interview could take place either in a side room or in one corner of the waiting area and that respondents would not need to wait longer to see the doctor. If an interview was interrupted by the doctor calling for the patient, the interviewer tried to complete it once the consultation was complete.

Responses were usually written down during the interview. Additional comments and elaborations were also noted, even if not directly relevant to the questions posed. The interviewer was asked to write down responses and comments as near *verbatim* as possible. The completed questionnaires were then split into separate sections with all responses to individual questions grouped manually and reported with accompanying quotes to indicate the range of comments given by respondents.

The aims of the interviews were testing the feasibility of systematic interviews with Travellers in a health centre and "field" settings and an initial characterisation of Traveller views to inform health service policy and priorities. Although comparison of views with those of the settled population using the same framework of questions would have been interesting, this was excluded by time and resource constraints. I asked the interviewer to keep a log of encounters with Travellers on sites and in the practice, including the problems she faced obtaining and completing interviews and drew on this information in my analysis of the interview results.

CHAPTER FOUR: RESULTS

4.1 Survey of primary health care providers

This section combines results of the questionnaire to East London general practitioners and community medical officers with a review of the work of the Travellers' health visitor with responsibility for East London.

4.1.1 General practitioner and community medical officer questionnaire

I had three aims in surveying all general practices in Tower Hamlets and Hackney and all community health clinics in Hackney: (a) identification of practices with a significant number of Traveller patients who I could invite to join the epidemiological study, (b) assessment of knowledge about and liaison with the Travellers' health visitor in East London and (c) identification of the problems which general practitioners and community medical officers experienced in providing health care for their Traveller patients. To some extent aims (a) and (c) conflict: the former requires the questionnaire to be linked to a particular practice which removes the advantage of anonymity when posing questions which may reflect on a doctor's attitudes and prejudices.

Questionnaires (appendix A) were sent to 103 practices in June 1988. Forty seven practices returned the initial questionnaire. Another seven returned the second questionnaire they received. Twenty two practices sent back the questionnaire after telephone reminders and twenty four answered the questions when the questionnaire was administered over the telephone. Only three general practitioners ultimately refused to answer the questionnaire. Similar questionnaires were sent to the community medical officers running child health clinics in City and Hackney health authority. All were returned after telephone reminders.

Table 4.1 Acceptance of Travellers as Temporary residents

YES	NO
90	10

Table 4.2. Any Travellers attended in past 12 months

	YES	NO	AMBIGUOUS RESPONSE
GP	25	72	3
CMO	5	4	-

The responses to the rest of the questionnaire were supposed to be from the 25 practitioners (and five community medical officers) who had seen Travellers in the past year, but 10 other GP respondents also completed all the questions. I present these groups separately (T = have seen Travellers in past year, NT = have not seen Travellers in the past year).

Table 4.3 Approximate number of Travellers seen

	< 1/month	1/month	1/week	> 1/week
GP(T)	7	7	5	6
CMO	3	2	-	-

Table 4.4 Permanent notes or temporary resident forms

	Permanent	FP19's	Both	No response
GP(T)	10	10	4	1
GP(NT)	2	7	-	1

Table 4.5 Knowledge of Travellers' health visitor

	YES	NO	NO RESPONSE
GP(T)	14	10	1
GP(NT)	1	9	0
CMO	4	1	0

Table 4.6 Contact with Traveller health visitor

	YES	NO	NO RESPONSE
GP(T)	8	16	1
GP(NT)	1	9	0
CMO	4	1	0

Table 4.7. Issues arising in the care of Travellers

	often	some times	rarely	never	no response
		appointment problems*			
GP(T)	13	3	1	3	1
GP(NT)	2	1	2	3	2
GP(CMO)	No appointments in child health clinics				
		continuity problems			
GP(T)	16	7	1	1	0
GP(NT)	5	1	2	0	2
GP(CMO)	4	0	0	0	1
		Lack of information			
GP(T)	20	4	0	0	0
GP(NT)	6	1	2	0	1
CMO	3	0	1	0	1

*Four practices did not have appointment systems and are not included.

Table 4.8 Usefulness of more information about Traveller culture

	YES	NO	NO RESPONSE
GP(T)	21	3	1
GP(NT)	7	2	1
CMO	4	0	1

Table 4.9 Willingness to participate in project to improve health care of Travellers

	YES	NO	NO RESPONSE
GP(T)	10	9	6
GP(NT)	5	4	1
CMO	4	1	0

Five practitioners added comments to the questionnaire sheet:

> I feel I know more about Travellers than social workers etc.
>
> We know there is a specialist health visitor but don't know where to contact her.
>
> I can't distinguish Travellers from rootless and homeless.
>
> More information about Traveller culture would be useful but proximity and ability to respond *fast* and *sympathetically* far more important! Both rare in general practice?
>
> We send Travellers to Well Street [a neighbouring practice] - we are not equipped to treat them.

Telephone conversations with general practitioners who did not return the initial questionnaire also generated two interesting comments:

> I'm not interested in Travellers, so I didn't return the form.
>
> I am a one-man practice, so I have no time for answering questionnaires. They go by the board.

4.1.2. Review of Travellers' health visitor role

Most initiatives around Traveller health care have included a specialist health visitor, but their methods vary with the level of support available to them, their catchment area and the problems of the specific Traveller community they serve, as well as their own perception of priorities (Durward 1990, Cornwell 1984b). In order to assess the health care of Travellers in Hackney I needed to characterise the activity of the specialist health visitor in Hackney.

In September 1981 a health visitor was appointed to work with Travelling families in City & Hackney, Islington and Tower Hamlets Health authorities. The post was initially funded through the inner city partnership scheme after pressure from a local general practitioner and other groups interested in Travellers, particularly teachers. Although not backed up by a formal survey, these groups felt strongly that Travellers were not receiving the health care they were entitled to under the 1948 NHS Act. Prior to the establishment of this post, visiting of Traveller families with infants was the responsibility of the health visitor whose patch included the site on which Travellers were encamped. This meant that as soon as Travellers moved on, continuity of care was lost and it was impossible to follow up childrens' development or pursue health promotion. The Travellers' health visitor is able to keep in touch with families throughout most of northeast London and, in principle, liaise with similar specialist workers in areas where families from Hackney often travel (Haringey, Wolverhampton, Woolwich, Kent).

- Discussion with post holder

Several discussions with the current post-holder, revealed a diversity of roles extending beyond a traditional model of health visitor activity.

Community development: the marginalised position of Travellers in London, particularly those on temporary sites resulted in isolation and fragmentation of the community. The Travellers' health visitor (THV) liaised with Travellers' support groups, Travellers' representatives, Travellers'(local authority) officers, environmental health officers, police and the courts. Her office was a postal address for mobile Travellers and she could organise hospital and other appointments. By working with individual families and becoming trusted, she became known to the Traveller network and was a focal point for various Traveller groups in their relations to the majority community.

Health promotion and health education: There was no formal health education programme for Travellers in Hackney. The THV provided impromptu health information as opportunities arose or when Travellers requested them. Some of this

information would be followed up with more discussion and leaflets where appropriate. But written material had limited application because of the high non-literacy rate. Common topics were feeding practices, prevention of gastroenteritis, care of sick children, women's health and prevention of accidents.

Facilitating use of services: In an attempt to counter the poor use of health services by Travellers and the (perceived) over-reliance on casualty departments for primary care, the THV informed Travellers about available services (child health, antenatal, family planning and dental clinics as well as general practices in the area of the caravan site), their opening times and location and often helped to make appointments. If Travellers were anxious about consultations, she would accompany them, particularly to hospital. The THV considered liaison with local general practitioners who see Travellers a central part of her role and helped develop record systems which allowed temporary notes to be retained in two practices.

Substitute roles:
DOCTOR - Not accustomed to the role of the family doctor or finding access to the general practice service difficult, Travellers would consult the THV about medical conditions which settled people would probably take to their general practitioners.
SOCIAL WORKER - Social workers tended not to be involved with Travelling families and initial contact - if made - would soon be broken if the family moved on. The THV was often the first professional to be made aware of a social or mental health problem and the only professional able to maintain contact.
WELFARE RIGHTS ADVOCATE - Because of non-literacy, no fixed address and ignorance of entitlement, many Traveller families failed to get welfare benefits. Travellers claiming unemployment or supplementary benefit were often referred to the fraud unit of the local social security office. The THV had a key role in putting the case for Traveller families to social security officers.

This description of the Travellers' health visitor's role was her own. The study group designing the evaluation of her work were surprised by the wide range of tasks she took on as well as the large catchment area within which she operated (boroughs of

Camden, Islington, Hackney and Tower Hamlets). It was also clear that her aim of improving health care was implemented through attempts at integration of Travellers into clinics and general practice surgeries, rather than a systematic outreach programme of, for example, immunisation or antenatal services.

- Retrospective record

Sites: During the study period there were between 11-16 sites in the THV's area, predominantly in Bloomsbury and Hackney. On average the THV visited six sites/week.

Population: The number of trailers varied from 100-300. Accurate estimation of the Traveller population was difficult. Five hundred to one thousand Travellers lived lived within the East London and Camden/Islington area at any one time.

WORKLOAD (Comparison with Bloomsbury health visitor workload)

Table 4.10 Number of clients seen by THV

	Travellers' health visitor	Bloomsbury health visitor
clients/week	24-240	12-30
average/week	92	19
aged < 5 year	45%	45%
aged < 1 year	7%	22%

MORBIDITY

The THV had contact with an average of four clients/week with disabilities. The Bloomsbury health visitors had contact with an average of one person with a disablility every two weeks.

TIME

Table 4.11 Division of THV activity

Over the three month study period the THV divided her time per week as follows:

Activity	units of time*
visits to sites	5
office	2
meetings	1.5
other	1
leave	1

* one unit = one half-day

- Prospective record

These data were collected from a log completed by the Travellers' health visitor (Appendix C).

MORBIDITY

Over the two-week period the THV saw 13 people with serious medical problems, eight people with disabilities and 13 with minor complaints or requiring treatments. The serious medical problems included repeated attempts to persuade a mother to allow her baby with failure to thrive to be admitted for investigation, uterine rupture following a stillbirth, severe depression following another stillbirth, a patient with schizophrenia not receiving regular chemotherapy and a poorly healed elbow dislocation. The disabilities included cerebral palsy, speech delay and hearing problems.

PREVENTIVE CARE

childhealth: ten immunisations discussed, eight children weighed, ten developmental assessments, one Guthrie test. Health education discussions focused on watering down babies feeds, adding cereal to feeds and prop-feeding babies. These are still common

practices within the Traveller community.

family planning: thirteen discussions including rubella screening, cervical smears and infertility.

antenatal care: four women given antenatal consultations.

BENEFITS

20 discussions including maternity grant, clothing grant, nappies for handicapped children.

ENVIRONMENTAL HEALTH

Seven discussions mostly concerning (lack of) toilet provision and rubbish disposal.

LIAISON

Fifteen discussions with (12) other health workers and 13 with social workers, education welfare officers, head teachers etc. In all 56 telephone calls with 40 people.

TRAVEL

Fourteen hours travelling to caravan sites (almost one fifth of time).

4.2. Descriptive epidemiology from primary care

Data were collected in Queen Elizabeth Hospital between July 1988 and September 1989 and in the practices between September 1988 and February 1990 . Collection of control data in the practices extended for four months after the last Traveller was recruited. Below I characterise the sample by a number of parameters: age, place of recruitment, address given. Where variables were not filled in on the data cards or laboratory results were lost they were coded as "missing".

4.2.1 Statistical methods

All X^2 and p values were calculated with a continuity correction for small sample sizes (Yates correction). If more than one cell of the 2X2 table had less than 5 values, Fisher's exact test was used. All *t*-tests comparing means (of normally distributed data) used a pooled variance estimate if the variances were significantly alike on F-testing ($p < 0.05$). Otherwise a separate variance estimate was used. All power calculations were for a power of 0.85 at the 0.05 significance level. All confidence intervals were calculated at the 95% level. When percentage columns in the tables do not add up to 100, this is due to rounding errors.

4.2.2 The sample

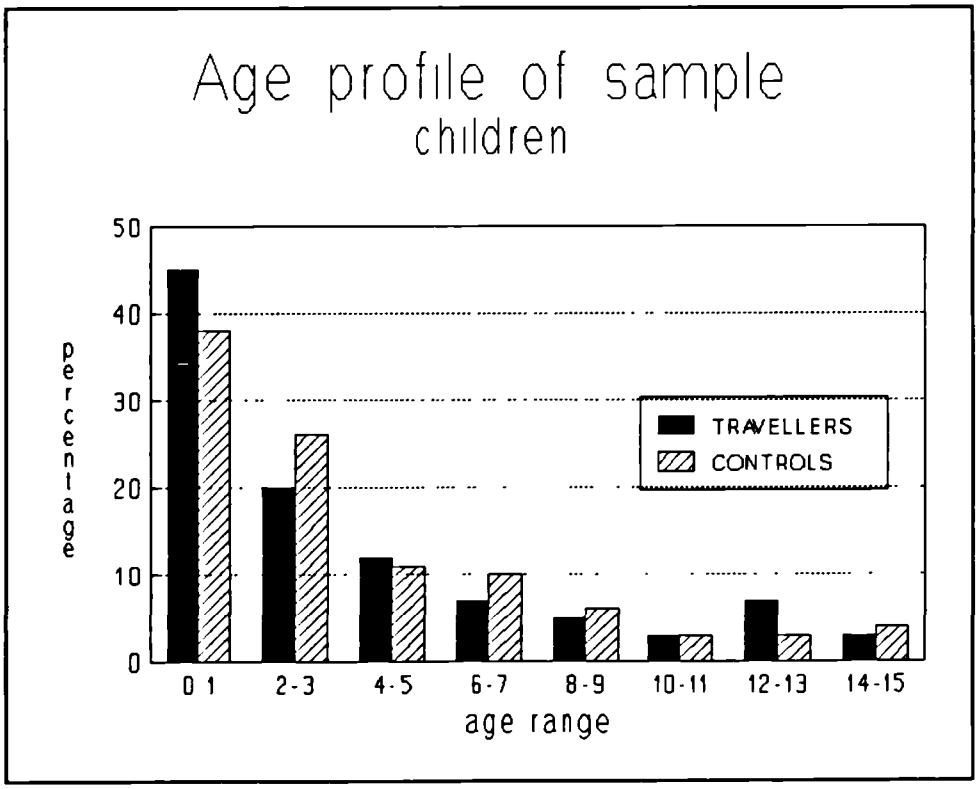
At Queen Elizabeth Hospital the maximum number of Travellers and controls eligible for the study was crudely calculated from a retrospective analysis of the accident and emergency department record book, counting all patients entered with a caravan site address or a known Traveller family name. In the practices, all Traveller notes were examined to arrive at the total number seen by doctors during the study period.

Table 4.12 Recruitment

Sample	Potential number	Number recruited	%
Queen Elizabeth Hospital			
Travellers	102	45	44
Controls	90*	72	80
practices			
Traveller children	148	107	72
Traveller women	96	72	75
Traveller men	43	21	49
Control children	214*	116	54
Control women	144*	69	48
Control men	42*	17	39

* Double the number of Travellers recruited

Graph 4.1



Graph 4.2

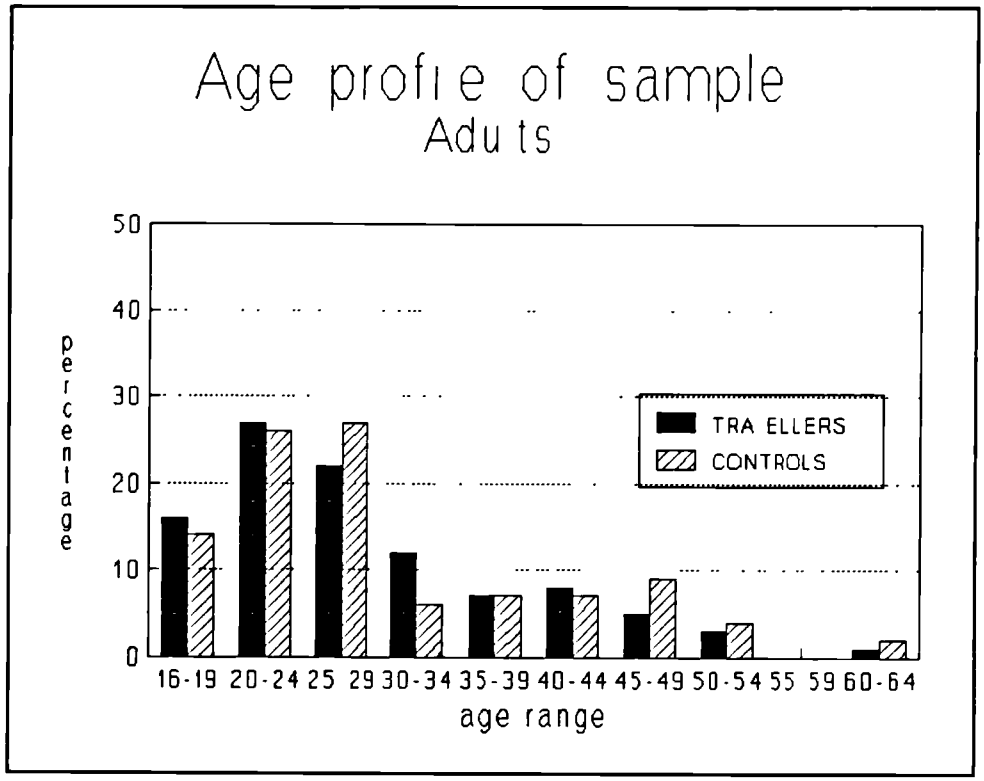


Table 4.13 Age structure of child sample

	Queen Elizabeth A & E				General practices				Total			
	TRAVELLER		CONTROL		TRAVELLER		CONTROL		TRAVELLER		CONTROL	
Age Range	num	%	num	%	num	%	num	%	num	%	num	%
0-1	25	56	24	33	43	40	47	41	68	45	71	38
2-3	9	20	21	29	21	20	29	25	30	20	50	26
4-5	5	11	8	11	13	12	12	10	18	12	20	11
6-7	2	4	6	8	9	8	12	10	11	7	18	10
8-9	0	0	6	8	7	7	5	4	7	5	11	6
10-11	1	2	2	3	4	4	3	3	5	3	5	3
12-13	3	7	3	4	7	7	3	3	10	7	6	3
14-15	0	0	2	3	3	3	5	4	5	3	7	4
Total	45	100	72	99	107	101	116	100	152	102	188	101

Table 4.14 Age structure of adult sample

	TRAVELLERS		CONTROLS	
Age range	Number	%	Number	%
16-19	15	16	12	14
20-24	25	27	22	26
25-29	20	22	23	27
30-34	11	12	5	6
35-39	6	7	6	7
40-44	7	8	6	7
45-49	5	5	8	9
50-54	3	3	3	4
55-59	0	0	0	0
60-64	1	1	1	2
TOTAL	93	101	**86**	102

Table 4.15 Sex distribution of sample

	ALL ADULTS		WOMEN		MEN	
	Travellers	Controls	Travellers	Controls	Travellers	Controls
Number	93	86	72	69	21	17
Range	16-63	17-64	17-63	17-63	16-58	18-59
Median	27	26	25	26	32	32
Mean	30.2	31.7	28.7	30.9	35.3	34.7
St dev	11.3	12.0	10.4	11.4	13.0	14.3

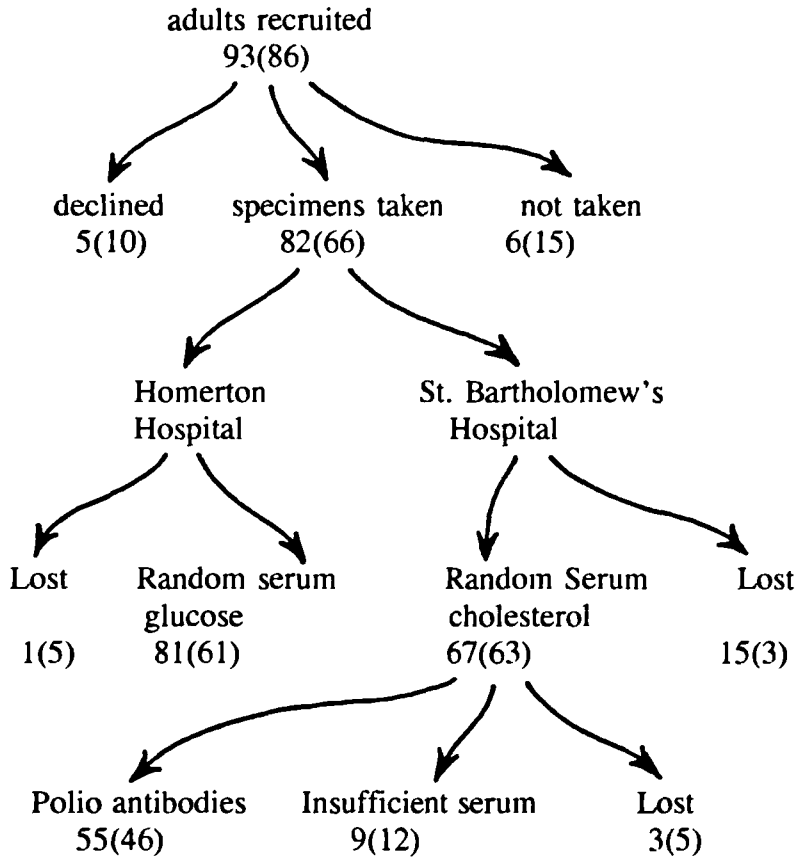
	TRAVELLERS		CONTROLS	
	Number	%	Number	%
Men (> 15 years)	21	9	17	6
Women (> 15 years)	72	30	69	25
Boys	79	32	100	37
Girls	73	30	85	31
Children*	0	0	3	1
Total	245	101	273	100

* sex not coded

The age structure and sex distribution of the adult Traveller and control samples are similar, allowing comparison of age-dependent variables such as blood pressure. The total child sample is also comparable, although there is a higher proportion of children aged under 2 years in the Traveller sample. Exact matching of the child sample is not important, as the variables I am studying are either independent of age (birthweight) or age-standardised (immunisation and growth status). Only one Traveller was recruited twice, first in one of the practices and, five months later, in the accident and emergency department. Only data from the second encounter was used.

A general practitioner's name was given for 8/45 (17%) Traveller children recruited in the accident and emergency department and 65/72 (90%) control children. This implies that the Traveller subgroup recruited at Queen Elizabeth Hospital has substantially less contact with general practice then the subgroup recruited in the two practices.

Table 4.16 Fate of blood specimens (controls in brackets)



A higher proportion of control than Traveller patients either declined to give a blood specimen or the doctors seeing them did not request the specimen. There are a large number of lost cholesterol specimens, mostly from the first quarter of the study when arrangements with the Lipid laboratory temporarily broke down (twenty specimens were accidentally sent back unanalyzed to the Homerton lab and discarded). Seven of those Traveller patients who re-presented in the course of the study allowed repeat venesection. The control sample was not effected to the same extent, because of the lag time between recruitment of Travellers and controls.

The smaller number of blood samples reduces the power of the study to detect differences between Travellers and controls. Analysis was still possible because of the similar age structure of the Traveller and control patients in whom glucose, cholesterol levels and polio antibody results were available.

Place and type of residence

These data were not collected from Travellers presenting to Queen Elizabeth Hospital. In the practices the information about address was taken directly from the patients' Temporary Residents form (FP19), which was often completed by the receptionist for the patient. For Travellers registered with the practices (19) the address was taken off the cover of the notes.

Table 4.17 Type of residence

STATED TYPE 0F RESIDENCE	NUMBER	%
Caravan	116	58
House or flat	61	31
Missing data	23	12
Total	200	101

Table 4.18 Place of residence

BOROUGH OF RESIDENCE	NUMBER	%
Hackney	158	79
Haringey	11	6
Tower Hamlets	8	4
Islington	2	1
Greenwich	1	<1
Waltham Forest	1	<1
MISSING	19	12
TOTAL	200	102

23/181 (%) of Travellers for whom the information was available gave an address outside Hackney and 15/181 (%) gave an address outside the Family Health Service Authority. For reasons I discuss in chapter five (p.150), this information about residence is unreliable and does not necessarily represent where Travellers were living on the day they were recruited into the study. It almost certainly over-estimates the proportion of Travellers staying in Hackney.

4.2.3 Child Health

Birthweight

Table 4.19 Birthweight distribution

	TRAVELLERS		CONTROLS	
RANGE(kgs)	Number	%	Number	%
<=2	2	2	2	1
2.1-2.5	7	6	12	7
2.6-3.0	16	13	34	20
3.1-3.5	36	30	70	42
3.6 -4.0	37	31	36	22
4.1-4.5	20	17	13	8
4.6-5.0	2	2	0	0
TOTAL KNOWN	120	101	167	100
Not known by parent	10	_	3	_
Missing	22	-	18	-
TOTAL	152	_	188	_

Graph 4.3 Birthweight distribution

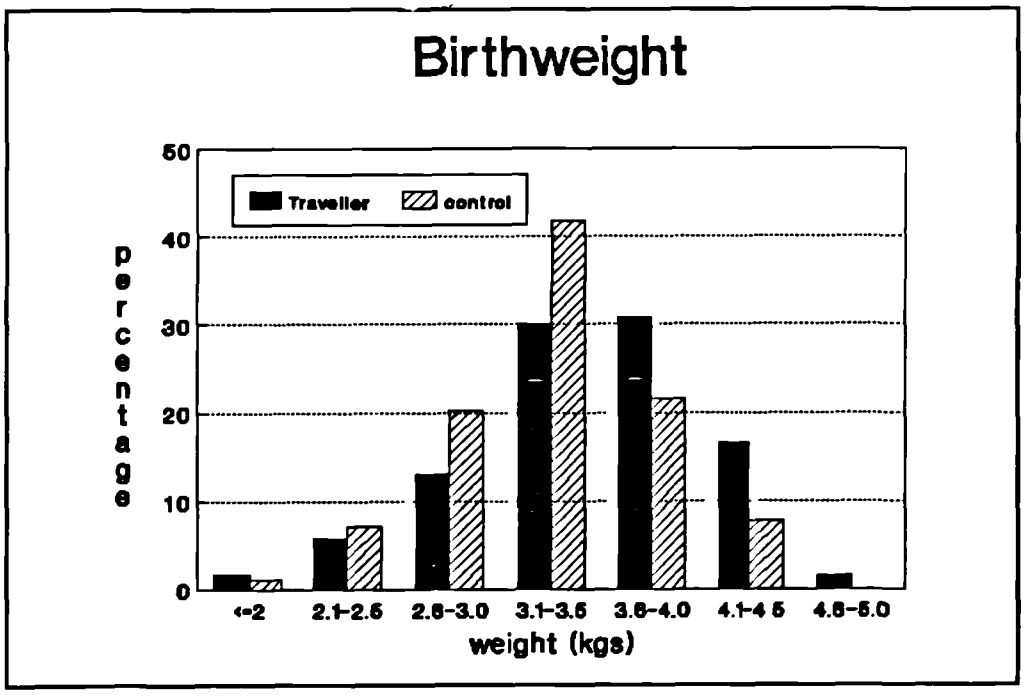


Table 4.20 Comparison of low birthweight and high birthweight incidence

	TRAVELLERS		CONTROLS					ENG LAND& WALES 1988	HACK NEY (1988)**
WEIGHT (kgs)	No	%	No	%	X^{2*} p	% diff	95% con.in	%	%
≤2.5	9	7.5	14	8.4	0.7 0.79	1	-7.2 to 5.4	6.8	9.3
>4	25	20.8	13	7.8	9.2 0.002	13	4.7 to 21	-	-

* one degree of freedom

** City and Hackney Health Authority 1990.

There is no difference between the proportions of low birth weight babies in the Traveller and control samples. Although both are higher than the proportion nationally in 1988, the proportion for Hackney in that year is still higher, the third highest of the 160 health districts in England. The practice-recruited Traveller subsample has a *higher* proportion of low birth weight babies than the Queen Elizabeth babies (9.1 vs. 4.7%) but the wide confidence interval for this difference (-4.6 to 13.4%) means that the sample is not sufficiently large enough to detect a difference of this size. Travellers had a significantly higher proportion of babies weighing more than four kilos than the control sample. Both Traveller and control samples approximate a normal distribution and have similar variances, allowing use of the t-test to compare means.

Table 4.21 Comparison of mean birthweights

	TRAVELLERS	CONTROLS	t p	Diff means	95% conf interval
Mean weight	3.48	3.28	3.08	0.2	.07 thru 0.33
Standard error	0.5	0.4	.002		

Mean birthweight is significantly higher in the Traveller sample. Mean birthweight was also analyzed for children aged less than one year old to exclude possible inaccuracies in recall for birthweights in older children. The mean birthweights for these very young Traveller and settled children were similar to the larger sample: 3.46 and 3.28 kgs respectively. The higher mean birthweight of Traveller babies reflects the higher proportion of high birthweights compared to the control sample.

Growth

Table 4.22 Weight of children presenting to Queen Elizabeth Hospital accident and emergency Department

	TRAVELLERS		CONTROLS	
Centile range	Number	%	Number	%
≤3rd	3	9	4	8
4th-10th	1	3	4	8
11th-25th	10	4	10	20
26th-50th	1	30	10	20
51st-75th	8	24	7	14
76th-90th	5	15	6	12
91st-97th	3	9	4	8
>97th	2	6	6	12
TOTAL	33	100	51	102

The recorded weight was converted into a centile position using the growth charts of Tanner and Whitehouse (1974). Weight was not recorded in 12/45 Traveller and 21/72 control children respectively. This is a problem not only because the sample size has shrunk but also because there is the danger of systematic bias if the decision not to weigh a child was in *any* way related to perception of the child's weight.

There was no significant difference between the proportion of underweight (≤3rd centile) in the Traveller and control samples. The sample size was small, with confidence intervals for the difference between the Traveller and Control samples

ranging from -11% to 13.5%.

Only 13/49 and 29/62 control children had height measured. These results are not analyzed. The majority of children whose height was not measured were under 2 years of age. Either they did not cooperate with the nurse or there was reluctance to bring out the device for measuring supine length, which is not used routinely in the accident and emergency department.

Primary immunisations

This part of the study was based on parental reports of immunisations on direct questioning by general practitioners in the practices or nurses in the Queen Elizabeth Hospital accident and emergency department followed by validation from the district database and manual records.

IMMUNISATION STATUS

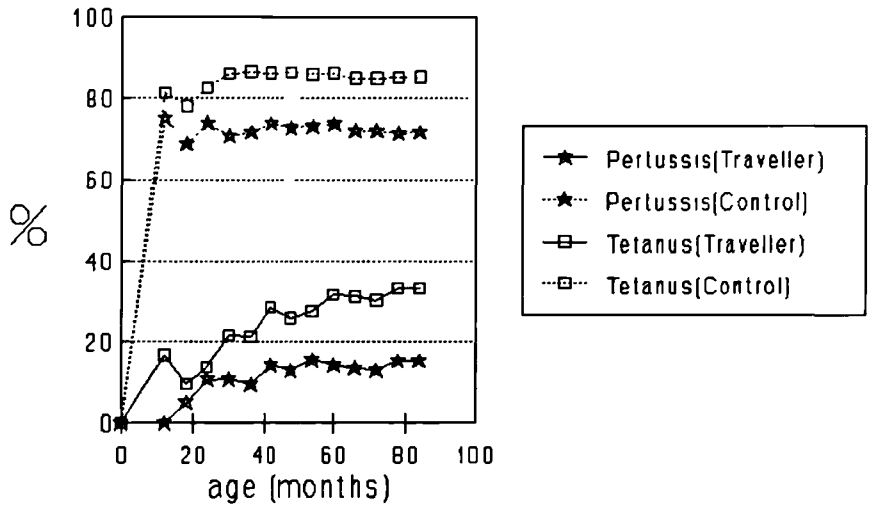
Seventy-two Traveller and 106 control children were eligible for an assessment of immunisation status (see p. 66)

Table 4.23 Completion of primary course of immunisation in all eligible children entered (%)

	TRAVELLER		CONTROLS				Hackney (1991)
VACCINE	numb/total	%	numb/ total	%	Differ ence	95% c.i.	%
PERTUSSIS	11/72	15	71/106	67	56*	44-68	79
DIP/TET	24/72	33	90/106	85	52*	39-64	82
POLIO	22/72	31	92/106	87	56*	44-69	82
MEAS/MMR	12/61	20	60/85	71	51*	38-65	80

* X^2 test $p < .0001$, d.f. = 1

Graph 4.4 completion* of primary tetanus and pertussis course



* cumulative %

Table 4.23 shows the extremely low completion rate for the triple antigen, polio and measles primary course of Travellers in Hackney even compared to an inner city population with lower reported immunisation rates than the national average.

Graph 4.4 shows that the Traveller completion rate for tetanus continues throughout the age range studied (polio shows a similar pattern) whereas the pertussis completion rate is relatively static by two years of age.

Table 4.24 Proportion of children having first immunisation but not completing course

	TRAVELLER		CONTROLS			
VACCINE	numb/ total	%	numb/ total	%	Difference	95% conf.int
PERTUSSIS	8/19	42	10/85	12	32*	7 to 54
DIP&TET	27/51	53	14/104	13	39+	24 to 55
POLIO	26/48	54	12/104	12	42+	27 to 58

* X^2test p = 0.002

+ X^2 test p << 0.001

Table 4.24 shows the proportion of Traveller and control children who had the first immunisation but did not complete the primary course. Both Traveller and control sample have a "fall-off" between 1st and 3rd immunisations of all the components of the primary course, but the discrepancy is significantly greater for Traveller children. Half the Traveller children in our sample who had the first immunisations did not complete the primary course.

Table 4.25 Analysis of completed primary courses children in practices and in Queen Elizabeth Hospital

	PRACTICES		ACCIDENT &EMERGENCY			
	numb	%	numb	%	% Difference	95% conf. int
VACCINE		**TRAVELLER**				
PERTUSSIS	9/48	19	2/24	8	10*	-5 to 26
DIP/TET	18/48	38	6/24	25	13*	-10 to 35
POLIO	17/48	35	5/24	21	15*	-7 to 36
MEAS/MMR	9/41	22	3/20	15	7*	-13 to 27
		CONTROLS				
PERTUSSIS	52/67	78	23/39	59	19	0 to 7
DIP&TET	60/67	90	30/39	77	13	-2 to 27
POLIO	60/67	90	32/39	82	8	-7 to 21
MEAS/MMR	40/54	74	20/31	65	10	-11 to 30

*X^2 test; d.f.=1, p>.05 (N.S.)

Table 4.25 compares Traveller and control completion rates for the primary course between the practices and the accident and emergency department. Although absolute completion rates for all components of the primary course are consistently higher in the practices, these differences are not statistically significant.

VALIDATION OF PARENTAL REPORTS

Travellers: Using all locally available sources of data on recorded immunisations it was only possible to independently assess the immunisation status of 19/48 (40%) of children recruited in the practices and 6/24 (25%) of children recruited in Queen Elizabeth Hospital.

Controls: Immunisation records were available for 53/67 (79%) of the settled children seen in the practices. The 14 missing records belonged to children who had left the practices since the start of the study and were also not recorded in the child health record system. Independent validation for the controls recruited in the accident and emergency department was less successful. Information was only available on 9/39 children (23%).

Table 4.26 Evaluation of agreement for immunisations (Pa=parental report Re=record)

	AGREEMENT			OVER-REPORTING	
			TRAVELLER		
VACCINE	Pa/Re + +	Pa/Re - -	Kappa	Pa/Re + -	Pa/Re - +
1st pertussis	8	12	0.5	0	5*
3rd pertussis	7	14	0.6	2	2
1st dip/tet	20	4	0.9	0	1
3rd dip/tet	7	14	0.7	3	1
1st polio	19	5	0.9	0	1
3rd polio	6	15	0.6	3	1
Measles	5	14	1.0	0	0
			CONTROLS		
1st pertussis	50	9	0.8	0	3
3rd pertussis	40	13	0.6	5	4
1st dip/tet	60	1	0.9	0	1
3rd dip/tet	49	7	0.6	3	3
1st polio	59	1	0.8	0	2
3rd polio	50	6	0.6	3	3
Meas/MMR	38	4	0.8	0	2

* $p < 0.05$ (on Mcnemar test)

In Table 4.26 the Kappa statistics show good agreement between parental recall and immunisation records. The Mcnemar test was only significant for the first pertussis where it indicated a bias towards parents under-reporting the immunisation.

The immunisation rates of control children for whom records were available were similar to the total control sample, but immunisation rates of the Traveller children for whom other records were available were higher than the total Traveller sample.

This is because a high proportion of Traveller children had received no immunisations at all and were more likely not to be recorded either in health visitor records or the district record system making impossible validation of parental reports of "no immunisations".

4.2.4 Adult Health

polio immunity

The samples were taken from adult patients recruited in the practices, stored in the Virology department and run in one batch using a modified micrometabolic inhibition test for the presence of neutralising antibodies (titre < 5 = absent) for polio types 1-3.

Serum was available for 55 Travellers and 46 controls.

Table 4.27 Polio antibody distribution

POLIO ANTIBODY	TRAVELLERS		CONTROLS		X^2 / p	difference %	95% con int
	N°	%	N°	%			
I	51	93	43	94	0 1.0	1	-9 to 10
II	55	100	45	98	0.08 .93	2	-2 to 6
III	53	97	42	91	.5 .42	5	-4 to 14
All	50	91	38	83	.89 .35	8	-5 to 22

The control sample had a higher proportion of non-immune subjects but the difference in total immunity (all three antibodies) was not significant. The 95% confidence interval for the percentage difference between the 2 groups was wide (-5 to 21.6%). With this sample size, I would only have been able to detect a 25% difference in total immunity.

smoking rates

I asked participating general practitioners to record patient's report of smoking rate in terms of cigarettes/week. This information was recorded for 92/93 Travellers and 85/86 control patients. Previous smoking history was not elicited. I did not validate patient reports with other measures such as urinary cotinine. Although the risk of smoking-related diseases increases with increased tobacco consumption (Rose and others 1983) the relatively small sample size and the uncertainty in reporting smoking frequency led me to a simple analysis of smokers versus non-smokers in the Traveller and control samples.

Table 4.28 current smokers

	TRAVELLERS		CONTROLS		% Difference	X^2
	Number	%	Number	%	confid int	p-value
Women	44	62	24	35	27	8.9
					11 to 43	0.0029
Men	15	68	9	53	19	0.52
					-12 to 50	52
All	59	63	33	39	25	9.8
					11 to 40	0.0017

The smoking rate for Traveller women in my sample was significantly greater than the rate for control women and higher than any group in the 1988 household survey. The proportion of control women who said they smoked was more than the female smoking rate (30%) in the 1988 household survey and comparable to that of semi-skilled manual and personnel workers nationally (Foster and others 1988). The high smoking rate for Traveller and control men in this study exceeded all groups in the household survey.

Blood pressure

COMPARISON OF BLOOD PRESSURE MEANS

Despite a marked digit preference, the distribution of pressures was roughly normal so a comparison of means by a *t*-test was legitimate. An F-test for the diastolic results showed that the variances of the Traveller and control samples were not significantly different (.577), so the *t*-value was calculated from a pooled variance estimate. The variances of systolic pressure in the two groups were significantly different on F-testing (.017) so the *t*-value was calculated from a separate variance estimate.

Table 4.29 Mean systolic pressure

Mean systolic pressure	TRAVELLERS	CONTROLS	difference	t-value*
Number	81	77	confid int	2-tailed prob
Means	116.4	116.8	-0.4	-.20
			-5.1 to 4.1	0.84
std dev	14.2	15.1	* df=156	
Missing	12	9		

Table 4.30 Mean diastolic pressures

Mean diastolic pressure	TRAVELLERS	CONTROLS	difference	t-value*
Number	80	77	confid int	2-tailed prob
Means	72.1	71.3	0.8	0.42
			-2.8 to 4.4	0.68
std dev	12.7	10.0	* df=149	
missing	13	9		

Mean blood pressure rises throughout adult life in Western societies (Law and others 1991). In this relatively young sample it is possible that a real difference between older Travellers and controls might be masked. Therefore I also analysed mean systolic and diastolic pressures in the over-30's. There was no significant difference between the means in this subgroup, although the small size of the subgroup (30 Traveller and 33 controls) reduces the power of the comparison; it could only have detected an 11 mmHg difference in mean systolic and an 8 mmHg difference in mean diastolic pressure.

Table 4.31 Proportion of sample with diastolic pressure >90 mm Hg

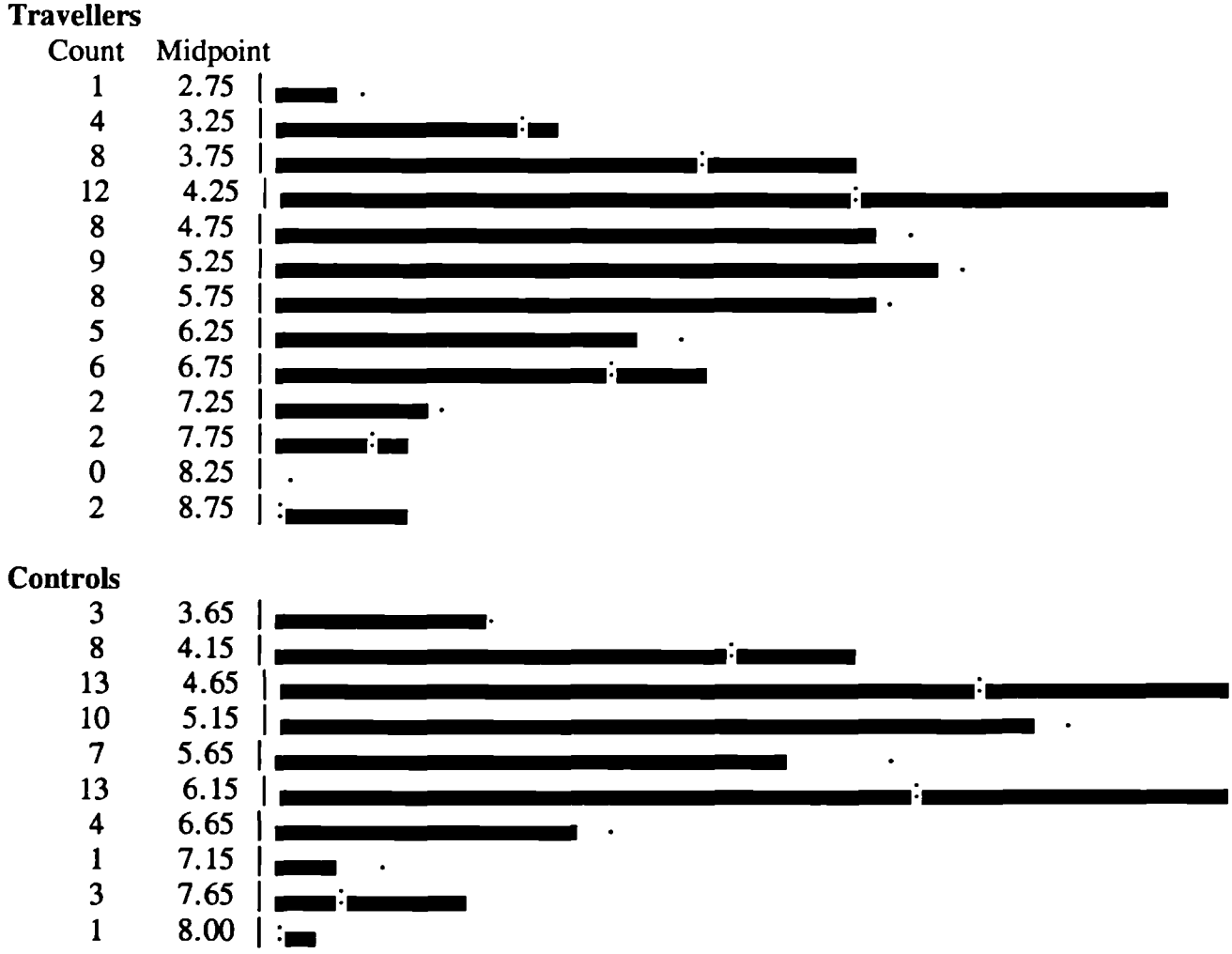
	Travellers		Controls		% difference (confidence int)
	Number	%	Number	%	
Normotensives	74	91	73	95	4 (-4.4 to 11.5)
Hypertensives	7	9	4	5	

The proportion of Travellers with a diastolic blood pressure of 90mmHg or greater in the 30 years and over age group was 6/32 (19%) and 2/32 (6%) in the control group. This difference is not significant on X^2 testing (p value of 0.26). To detect this 13% difference in the number of hypertensives I would have needed a total sample size of 240.

serum cholesterol

Sera from Traveller and control patients were analysed to determine a random cholesterol for each patient. The results were sent back to the practices and retrieved from the notes quarterly, during the study period.

Graph 4.5 Random serum cholesterol distribution (mmol/l)



. . . . . = normal curve

The mean value for Travellers was 5.12 mmol/l and for controls was 5.35 mmol/l; The serum cholesterol values have a skewed distribution, but fit a normal distribution when logarithmically transformed. Therefore the difference between the means of this transformed data can be compared with a t-test. I have also compared the proportion of patients with serum cholesterol greater than 6.5 and 7.8 mmols, thresholds for

specific dietary treatment and drug treatment respectively, as recommended by the British Hyperlipidaemia Society (Shepherd and others 1987).

Table 4.32 Mean log (serum cholesterol concentration)

	TRAVELLERS	CONTROLS	difference	t-value*
			confidence int	2-tail prob
Mean log [cholesterol]	1.60	1.66	0.06	-1.07
			-0.024 to 0.140	0.161
std dev	0.26	0.20	* df=128	
number	67	63		
refused	5	8		
not taken	14	13		
lost	7	5		

Using logarithmically transformed values, it is still possible to get a confidence interval for the difference between the Travellers and controls which relates to the original serum cholesterol values (Altman 1991). Using the anti-logs of the difference between the means of log [serum cholesterol] and the maximum and minimum values of the 95% confidence interval, it is possible to derive a ratio of the mean serum cholesterol values and a 95% confidence interval for this ratio: 1.08 (0.976 - 1.15).

There was no significant difference in mean serum cholesterol in this sample. With this sample size, I would have been able to detect a 0.66 mmol/l difference in means. With the exception of familial hypercholesterolaemia, serum cholesterol rise gradually in Western populations from 15 to 30 years (National Heart Lung and Blood Institute Collaborative Lipid Group 1987). Therefore if there was a difference between older Travellers and controls in our study populations this might be masked by taking means from a relatively young sample. To examine this possibility a subgroup of 26 Travellers and 28 controls more than 30 years old was analysed. There was no significant difference in mean log [serum cholesterol] in this subgroup, although a Type II error is possible with such a small sample.

Table 4.33 Proportion of sample with serum cholesterol >6.5 mmol/l

	Travellers		Controls		% Difference	X^2
Random cholesterol	prop	%	prop	%	confid int	p-value
Proportion >6.5 mmols/l	9/67	13	9/63	14	1	0
					-13 to 11	1
Proportion >7.8 mmols/l	2/67	3	1/63	2	1	0
					-4 to 7	1

Analysis of the data by serum cholesterol concentrations recommended as treatment thresholds also shows no difference between the two groups.

plasma glucose

Blood specimens in fluoride oxalate bottles were analysed by the glucose oxidase method to determine random plasma glucose levels in Travellers and controls. Results were compared categorically using the WHO criterion (WHO Study Group 1985) for the diagnosis of diabetes from a random plasma glucose: >11.1 mmols/litre.

Table 4.34 Prevalence of diabetes on random plasma glucose testing

	Travellers		Controls		% Difference	X^2
Random glucose	prop	%	prop	%	confid int	p-value
=>11.2 mmol/l	2/81	3	0 61	0	3	.26
					-1 to 6	.61
missing	12/93	13	25 86	29		

Detection of a 3% difference in the prevalence of diabetes between Travellers and control would have required a total sample size of 500.

alcohol consumption

General practitioners were asked to record consumption of alcohol in the past week of Traveller and control patients. The data were analysed both in terms of the "safe" consumption limit (up to 14 units per week for women and 21 per week units for men) and, with the aim of detecting unequivocal alcohol abuse, double the "safe" limit (28 units or more per week for women and 42 units or more per week for men).

Table 4.35 Alcohol consumption

	TRAVELLERS		CONTROLS		% Differ	X^2
Units alcohol/week	Number	%	Number	%	confid interval	p-value
			Women			
>14	5/65	8	3/63	5	3	0.10
					-5 to 11	0.75
>21	3/65	5	1	2	3	2.0
					-2 to 9	0.63
Missing*	7/72	10	6/69	9		
			Men			
>21	9/21	43	3/16	19	24	1.4
					-4 to 53	0.23
>42	6/21	29	0/16	0	21	3.9
					-5 to 47	0.28
Missing*	0/21	0	1/16	6		

* includes non-quantified information: "socially" "weekends","infrequently"

None of the differences between Travellers and controls were significant, although the confidence intervals in the comparisons between men suggested the possibility of a Type II error. To detect the differences in reported consumption between male Travellers and controls shown above I would have needed a total sample size of 130 (>21 units per week) or 140 (>42 units per week).

cervical smear rates

Table 4.36 Last cervical smear

	TRAVELLERS		CONTROLS	
LAST CERVICAL SMEAR	Number	%	Number	%
NEVER	20	28	8	12
"DUE"	1	1	1	1
REFUSED	2	3	1	1
1984	1	1	0	0
1985	0	0	2	3
1986	1	1	3	4
1987	10	14	6	9
1988	17	24	13	19
1989	8	11	27	39
1990	1	1	3	4
NOT ELIGIBLE	4	6	2	3
NOT KNOWN	3	4	0	0
HYSTERECTOMY	2	3	2	3
MISSING DATA	2	3	1	1
TOTAL	72	100	69	99

I had data for 61 Traveller and 64 settled women who were eligible[1] for a cervical smear. The sample size was small and most of the smears were in the past five years. Therefore, I compared the proportion of Traveller and control women who had *ever* had a smear. Recollection of ever having a cervical smear should also be more accurate than when the last smear was taken. The two women in whom the doctor recorded refusal of a smear were coded as never having one and the woman who was "due" a smear was assumed to have had a previous smear.

Table 4.37 Proportion of sample ever having cervical smear

	TRAVELLERS		CONTROLS				
CERVICAL SMEAR	Num	%	Num	%	X^2 / p	% diff	95% con.in
EVER	39	64	55	86	6.97 / 0.083	22	7.3 to 36.8
NEVER	22	36	9	14	9.2 / 0.002		

There was no difference in mean age between Travellers who had ever had a smear and those who had not.

[1] In both practices where cervical smear status was recorded women were elegible for a smear if they had ever had sexual intercourse.

4.3 Use of hand-held medical records

I requested that every Traveller patient entered into the study be given (by the general practitioner or accident and emergency nurse) a hand-held medical record card with relevant medical details including - for children - an immunisation record and - for women - a cervical smear information. 192 cards were given out (77% of all Travellers recruited). Travellers were asked to show the card to a nurse or doctor at every subsequent consultation either in Hackney or elsewhere. I monitored return of the detachable section of the card until February 1991. 59/192 were returned, demonstrating that the cards were used at least once by 31% of the Travellers in the study. The cards could not be traced back to individual Travellers, although I was able to classify use of the card by age and - in adults - sex.

Table 4.38 Hand-held records issued and returned

	Children		Women		Men	
	Prop	%	Prop	%	Prop	%
Record cards issued	122/156	78	58/72	80	12/21	58
Record cards returned	45/122	37	12/58	21	2/21	17

All the cards were returned from the three centres in which the study was based or from the Travellers' health visitor. None were returned either from other practices in East London or from outside of London

Lower Clapton Health Centre	32
Queen Elizabeth Hospital	9
Well Street Practice	11
Travellers' Health Visitor	7

The card had a question about whether the health visitor or doctor found the hand-held record useful and a space for comments. Two fifths found the card useful and the other three fifths either wrote that it was not useful or did not respond. Ten of the 16 respondents who wrote that the card was "not useful" specified that they already knew the patient or had issued the card in the first place. One wrote that she could not understand the immunisation information. Several wrote that the handheld record card duplicated information already in the hand-held child health card or hand-held antenatal notes.

Other comments:

> Previous history very useful. It listed recent investigations the patient already had for abdominal pain which stopped me repeating them.
>
> What about a growth chart?
>
> Since the issuing of the record, the client has been seen at the A&E London Hospital where it was shown. I had difficult extracting the [detachable] card from the client as she had been told not to part with the card.

4.4 Interviews with Travellers

4.4.1 Preliminary unstructured interview

Interviews with three Travellers were tape-recorded before writing a draft questionnaire. The initial informants were well-known to me: DM and JM are a couple in their early thirties with four children; MM is in his early sixties and has ten children. The interviews took place in their caravans (often called "trailers" by Travellers). In addition to helping me design the questionnaire, these unstructured in-depth interviews (two to three hour duration) cast light on some important issues.

- **Environmental conditions** were seen as a major influence on good health, more important than medical intervention or lifestyle factors like smoking or drinking. This prompted me to include a section on environmental facilities in the questionnaire.
- **Involuntary mobility** stopped Traveller getting treatment from doctors or help with chronic diseases. My initial informants expressed a longing for permanent sites which would still allow periodic travelling to stay with relatives.
- **Access to general practitioners** was not taken for granted. Repeated experience of doctors refusing to provide care made them wary about approaching practices in areas they were not familiar with. They expressed a willingness to travel long distances to see those doctors who would see them. They made no distinction between being registered or being seen as temporary residents.
- **Use of folk remedies**: MM discussed various remedies for different kinds of cough and for diarrhoea. I excluded questions about the use of folk remedies from the questionnaire because of its overall length.

4.4.2 Sample for questionnaire-guided interviews

Over a period of six months thirty-five adult Travellers were approached either on a caravan site or in the waiting area of a health centre. Twenty eight agreed to be interviewed. Although the overall refusal rate - 7/35 (20%) - is reasonable in a study where potential interviewees are approached unannounced on their doorstep or in a general practice waiting area, there was also a high rate of incomplete interviews

(7/28).[2] The refusal rate was higher from Travellers approached on caravan sites (5/16), than those approached in the health centre (2/19). The formal refusal rate does not adequately reflect the difficulties in actually obtaining an interview. The interviewer often had to return to a caravan site several times to obtain an interview or in an attempt to complete one.[3] Individual interviewees, particularly when interviewed in their caravan, were often joined by a few friends and relatives who contributed to the discussion, sometimes answering questions in place of the nominal interviewee. This complicates analysis of the interview results.[4]

The sample was predominantly female (22 women 6 men) with a mean age of 33 years (range 18-62). Twenty four of the interviewees had children, two did not and the information was not recorded for another two. Number of children ranged from one to seventeen (mean number = 4.5)

The questionnaire format, even when modified, was often inadequate to contain the issues which Travellers themselves wanted to discuss: intolerance by local authorities, harassment, lack of education and caravan sites. The interviewer wrote down some of these comments along with direct responses to questions.

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[2] Notes from interviewer's log: "Interview No. 23 This interview was difficult...looking at what I had written she implied that I had written the opposite [of what she had said] - obviously wary of my motives...She seemed happier talking in an informal way without the questionnaire. There seemed no point in pursuing the interview."

[3] From the interviewer's log: 12 June 1990 **Visit Ash Grove Site:** No interviews done today, asked if I could come back another day.
14 June **Visit Ash Grove Site:** Met by a man who recognised me, no interviews done, asked to come back.
16 June Walked past Ash Grove Site to find every trailer gone."

[4] From the interviewer's log: "Taped interview with EM also daughter W, later joined by daughters T and M, Ash Grove Site...EM tended to be quite reserved...when there was hesitation over an answer she would look at her daughter for her to answer; during this time she would do something else like clear away cups and then rejoin us.

In order not to limit possible answers to questions and minimise cues about "correct" answers, most of the questions did not have pre-coded responses. I also tried to limit the number of closed questions. Nevertheless, the questionnaire/interview format often made Travellers uncomfortable, in contrast to the relaxed atmosphere of informal conversations. For example, a woman on a site had just declined to complete an interview started the week before, but then she and her mother fell into a long conversation with the interviewer.[1]

As the interviewer and myself became known to Travellers on the caravan sites we were asked to support them on a number of issues: provision of toilets and skips on two temporary sites, submission of a letter to the local authority ombudsman on the ten-year delay in providing a permanent site in Hackney and an appeal against a conviction which involved a visit to the High Court. Valuable in themselves, these activities also created a relationship of trust between us and some groups of Travellers which facilitated interviews with other Travellers and discussions about health needs.[2] Inevitably, these activities also resulted in less time available for increasing the number of interviews. Limits on my resources resulted in a relatively small number of interviews, which cannot be construed as a representative sample of Travellers in Hackney. Therefore, the main aims of the interviewing exercise became testing the feasibility of structured interviews for the exploration of Traveller views about health and health care as well as an initial characterisation of these views in relation to other parts of my study.

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[1] The interviewer noted afterwards: "Again I was struck how open this family was. They were interested in the research. But... they were happier to talk in an informal way about what was relevant and important to them, asking me questions about what I was doing [interviewer's log p.14].

[2] This trust was by no means universal. After I had visited a site and - with permission - took pictures for a lecture on Travellers' health, the interviewer visited the site for interviews. She noted in her log (15 July **Gransden Ave**) "I was then informed that her daughter would not be answering any questions and she would not either. I was then asked what right we had to go around taking pictures of Travellers. 'I've never heard of anything like it before, a doctor carrying on like that, going around taking pictures of Travellers. It's not right.'

Table 4.39 Place of interview

PLACE OF INTERVIEW	NUMBER
Lower Clapton Health Centre E5	17
Gramsden Avenue Caravan Site E8	3
Prout Road Caravan Site E5	3
Ash Grove Caravan Site E8	4
Morning Lane caravan site E9	1
TOTAL	28

Below I present the questions asked to Travellers (in bold), followed by a summary of the answers and direct quotes from the respondents. Where appropriate I also give the numbers of particular responses. The order of questions was varied in different interviews, although the questions about causes and prevention of illness were always asked before discussion of health services or preventive procedures. The number of people answering each question is given in square brackets next to the question.

4.4.3 Mobility

Most of the questions around mobility and origins were re-written after the first 6 Travellers were interviewed, because the questions were too vague, used terms which proved inappropriate for Travellers (ie. "settled in Hackney") or made the interviewees uncomfortable (eg. question about place of birth or about time spent travelling outside of Hackney). I have not included the abandoned questions in this report.

a. How long have you been based in Hackney?[25]

There was some reluctance to answer this question and we got the impression that the notion of being "based" somewhere was not appropriate to at least some of our interviewees. Eight of the interviewees who were seen in the Health Centre were in fact living in Haringey or Tower Hamlets which are adjacent boroughs. They had

given Hackney addresses to the receptionist. Of those 17 living in Hackney who answered the question, only two said they had been based here less than a year and eight said they had been based in Hackney more than five years.

b. **Do you live in a flat or a house or a trailer/caravan?**

Table 4.40 Place of residence of interviewees

Trailer	Flat	House	Portacabin
22	4	1	1

c. **In the past year how many times have you moved?**[22]

Travellers were puzzled by our desire to ascribe a number to their moves. Asking for the answer in terms of "once a year/month/week was not helpful, since the pattern was not constant for the past year. Defining a "move" was also not easy. Is going up to Manchester for two months to attend a wedding equal to a "move"?. One third had moved more than a dozen times in the past year, some claiming to have moved almost every week. Another third had not moved at all in the past year, which included five Travellers who were on official sites in Haringey and Tower Hamlets but returned to Hackney for their health care.

d. **Why have you moved?** [15]

This question was asked of the 15 Travellers who had moved in the past year. 11 had moved involuntarily at some point in the past year, with most families being repeatedly evicted from unofficial sites in East and North London.

> Hassle from police and council because the grounds are not proper sites.
>
> I think the council don't like you.
>
> People don't like us around.
>
> Police shifting us on. No where to go. Could move after a month or a week.
>
> Court order. We don't understand the reason. We just go when they tell us. Police put you out in the middle of the night. The kids suffer.

While these Travellers wanted to be able to spend more time on sites they had chosen, many said they would not necessarily want to stay on a site indefinitely and had also moved voluntarily. Four of the interviewees who had voluntarily moved in the past year expressed a clear preference for mobility.

> Haven't been hassled. Wife likes to move.

> Might be here today and somewhere else tomorrow. Definitely don't want to be in the same place.

e. Where did you move from?[15]

Despite its sensitive nature this question was included to clarify the geographical spread of mobility which may be relevant to the design of data networks (eg. immunisation status) or handheld medical record cards. Three quarters had moved within London, but only three from another site in Hackney. The other quarter came from Bradford, Birmingham, Ilford and Ireland.

4.3.4 Causes and prevention of illness [26]

a. What do you think are the main illnesses Traveller adults get?

This question provoked one angry response:

> That's stupid. It's [main illnesses?] never happened. It hope it never will happen to us. You can't tell until they get ill what it will be!

Although most Travellers were willing to answer the question they found it bizarre to list conditions in this way. They were much more forthcoming when they spoke about a specific person who had a specific problem (such as an uncle with lung cancer). Some of the respondents did not like the implication that Travellers might have different illnesses from the settled population.

Table 4.41 Adult Traveller "main" illness

ILLNESS	NUMBER MENTIONING
Respiratory*	11
"Flu"	6
other infections	5
Rheumatism & Arthritis	5
Cancer	4
Diarrhoea and vomiting	3
Injuries	2
Heart disease	1
Alcohol-related	1
Migraine	1
Don't know**	5

*including asthma, bronchitis and chest infection
** including non-specific reply such as "same as everyone else".

b. **What sort of things do you think make Travellers likely to get these illnesses?**

Almost three quarter of the respondents mentioned dangerous sites or the absence of environmental facilities (poor quality or total lack of toilets and water). The emphasis on environmental conditions was sometimes qualified.

> They say from dirty camps, rubbish, no toilets, no facilities. But sometimes people get ill on clean sites.

One quarter of respondents mentioned cold or dampness. Two explicitly mentioned eviction from sites.

> Police pulling you out at seven in the morning. Can be very abusive.
>
> They say we're not entitled to be here, should get out of the city. Some are O.K. Police say the minute we move into an area the crime rate goes up...

Only two people mentioned smoking and two mentioned diet as causes of "main

illnesses". Little mention was made of individual behaviour or "lifestyle" factors.

Traveller women with big families are very neglectful of themselves.

One quarter of interviewees did not give any specific causes of illnesses, saying that it "just happened".

c. What can adults do to look after themselves to help stop illnesses from happening?

Table 4.42 Means of adult illness prevention

PREVENTIVE ACTIVITY	NUMBER MENTIONING
Good sites with adequate facilities	12
Medical care only	4
Stop smoking	3
Stop alcohol	1
Stop self-neglect	1
Avoid ill people	1
Exercise	1
Live in house	2
Nothing	9

Although the question was phrased in terms of "looking after themselves", almost half the interviewees specified secure sites with good facilities as an important means of preventing illness. This is concisely summed up by one Traveller:

We would love a site. Have our own way of life.

More than a third of interviewees did not suggest any preventive solutions, personal or environmental:

Nothing really. If its there its there.

It just happens, there's nothing you can do about it.

Two interviewees who specified that only medical care could stop illnesses said that Travellers should always

> ...stay with one doctor. Important appointments could be missed if you moved on.

The two Travellers who mentioned living in houses as a method of illness prevention went on to qualify the point:

> Houses where it would be clean, with hot water and toilets could help stop illnesses and infections which we get from dirty places which sometimes we are moved on to. But we don't want to leave our trailers. It's our life. Houses are lonely, not the same, they don't feel right. We need a site where we can stay.

> Could pull into houses. But its wrong because it stops the generations of Travelling people. Shouldn't be forced to do that. Should have places to stop with facilities.

d. Regarding the health of children, what do you think are the main illnesses Travelling children get?

Table 4.43 Traveller children "main" illnesses

ILLNESS	NUMBERS MENTIONING
Diarrhoea and vomiting/gastroenteritis	13
Respiratory illnesses	10
Whooping cough	7
Measles	6
Colds and flu	6
Injuries	4
Kidney infections	3
Meningitis	3
Thrush	3
Polio	2
Other infections	3
Do not know	2

As with the similar question about adult illnesses, several Travellers were uneasy about listing childhood illnesses and were reluctant to specify them:

Just the children's troubles, same as the next child.

Some respondents pointed out that specific illnesses were used to stigmatise Travellers:

> Little boy got polio and the police locked the gates. Cashier would not take money for food because of the polio.

e. What sort of things make the children likely to get these illnesses?

Almost half the parents mentioned dirty sites, including sewage and contaminated water as a cause of childhood illness

> Fever from rats and skips.

> Infection comes from the camps, if we move into a dirty camp.

> The council won't help with water and toilets. Can pick up a bug from rubbish, depends where you're staying.

> Rusty nails and broken glass.

Cold and damp living conditions were specified by a few parents and diet by only two. A quarter of respondents mentioned infection from other children.

> Close living if one child get measles on site they all get it. Spreads in the air like whooping cough.

Two parents mentioned inheritance.

> Born with it in the blood [leukaemia].

And one mentioned poverty.

> Not enough money for food and clothes.

f. What can be done to stop these illnesses from happening?

PREVENTIVE ACTIVITIES	NUMBER MENTIONING
Good sites with adequate facilities	13
No evictions or more time on good sites	5
Immunisations	6
Keep away from ill children	2
Good medical care only	2
Hospitalisation	1
Shoes	1
Nothing	6
Don't know	1

Again, environmental considerations were uppermost, but a quarter of parents spontaneously mentioned immunisations specifically for polio, diphtheria and tetanus. Despite identifying whooping cough as a "main illness", no mention was made of the vaccine.

> Toilets, clean place, skip and water. Transit sites while waiting for a permanent site.

> With my kids I've not had any trouble with illness. They had all their needles done - it helps an awful lot.

> Gastroenteritis - take the children straight to hospital so that other children don't pick up infection. Then when they get well, take them out of hospital quickly because older children come in ill and can cause another illness.

> Trying to keep the kids and the caravan clean does not stop illness. There's nothing you can do to stop illness.

> Kids need breathing space. Make sites for Travelling people.

4.4.5 Health care professionals and services [25]

a. **What about going to see a doctor in Hackney? Have there ever been times when you or your child needed to see a doctor but couldn't?**

A quarter of respondents said they had been turned away from a surgery in Hackney or, in one case, were refused a home visit.

b. **Why?**

> Didn't have an appointment.
>
> Doctor won't come out because you're a temporary patient.
>
> Refused when not registered, so we have to go to the hospital.
>
> The kids had diarrhoea and they wouldn't take us on, so we had to go to hospital.
>
> Came with the baby for his third needle and wanted to see a doctor because his toe was festering. In the baby clinic she said they didn't see children that big [12 months?].
>
> Wouldn't let me see the doctor. I had the baby with me. It was sick. Wouldn't see me as temporary patient. Some don't like Traveller people.

c. **And in the past or when you've been travelling, have you ever wanted to see a doctor but couldn't?**

Over two thirds of respondents said that at some point they had been turned away from a surgery outside of Hackney. The rest had not had this experience, but seemed to take it for granted that it happened often to Travellers.

> Never tried. Always come back to Hackney to see the doctor. [four of the Travellers said they always returned to Hackney for their medical care]
>
> I've never tried. But been told they refuse Travellers.

d. **Why?**

> They just say 'no' because you're not registered.
>
> If you're a Traveller everybody looks at you as though you're dirty.

The secretary wouldn't let me see the doctor.

Mostly you can't even get as far as the doctor.

In Bristol, doctor said I would have to pay for my own medical treatment.

Same thing wherever you go. Once you say you're in a caravan then that's it.

In Southall, White City, all over it happens. They make up some excuse like they're too busy or they haven't got any appointments left.

Sometimes the doctor is far away and there's no car to take me there. Sometimes they tell you they can't see you because you're not registered there. But mostly I can get back here to see the doctor that knows us.

Sometimes doctor is miles away and you don't have any [medical] cards. Often turned away from pubs and dances as well.

Sometimes people know you're a Traveller and some don't like Travellers. Can't find doctors if we are in a new place. Receptionists often turn you away.

Didn't have proper addresses.

She got turned away because she's not clever enough to know how to make them let her see the doctor.

They said they were not servants of the public.

e. Do you feel you are treated with respect [by general practitioners]?

Three quarter of interviewees said they were, often qualified with "by some" or "in some places". A quarter expressed some cynicism about or lack of trust in doctors

Even if you earn it, you don't get it.

Some won't even examine you.

Some think because you're a Traveller you neglect the baby or don't keep your place clean.

f. **Do you understand what doctors say to you?**

Two thirds expressed satisfaction with the way doctors communicated information.

> When you tell them you can't read or write.
>
> They always tell me what's wrong.

One third were dissatisfied with this aspect of care.

> Just writes a prescription and don't tell you what's wrong or how to take it.
>
> They just give you something and don't explain.
>
> Sometimes you can't understand. They use long words.

g. **Do you have a health visitor? What is her name?**

Three quarter of respondents said they did and of these respondents *all* knew the name either of the Travellers' Health visitor in Hackney or in Haringey. Of those Travellers who said they did not have one, three were men and three, although interviewed in a health centre in Hackney, lived in an area which had no Travellers' health visitor (Waltham Forest). We omitted to ask if Travellers knew how to contact their health visitor.

h. **About what sort of things would you want to talk to her?**

Table 4.44 Subjects for discussion with the Travellers' HV

"Anything/Everything"	8
"Yourself/Stress"	5
Child health	5
Medical problems	3
Appointments	3
Post/communications	3
Immunizations	2
Women's health	1

She's a good woman. Has helped us a lot. I don't want to talk about it.

She's open-minded. If I need her I know she'll come round.

She's useless. She should have been here when I came out of hospital. My granddaughter is 18 months old and she's never seen her.

i. **What sort of illnesses would make you go to see the doctor?**

Only two thirds of interviewees responded to this question and most found it puzzling, even after explanation that we were interested in what made people go to the doctor rather than treating the illness at home. About a one third of respondents mentioned severe or childhood illnesses. Several mentioned a high fever, pregnancy or a "heart problem". Other illnesses or conditions were mentioned once: asthma, infection, worry, eye problems, cough, stomach pain, headache, immunisations family planning.

j. **What would make you more likely to go to a surgery or to a hospital?**

Most respondents said this depended on the situation. Reasons for using the hospital (accident and emergency department) included illness at night, severe illness, better equipment, no appointments needed, shorter waiting time, fewer questions, a closed surgery or being turned away from a surgery. There was no systematic distinction between primary and secondary care or any spontaneous recognition of general practitioners as "gate keepers" of secondary care. The only explicit reason for using a surgery was that doctors had their "files".

k. **I expect doctors and the health visitor come to the site when there are emergencies. Do you think there is any need for doctors or nurses to come out to sites at other times?**

A quarter of interviewees did not think there was a need for non-urgent visits by health care professionals, several mentioning the problem of privacy or confidentiality. The rest of the respondents were strongly in favour, specifying groups for whom it was particularly appropriate.

Some are shy and won't go to the doctor.

A lot of people won't go...some can't get to the doctor.

Some women can't use the 'phone to make an appointment.

Some women have too many children to look after [mentioned three times].

For older ones who don't go to the doctor.

For men.

Several people mentioned that visiting sites would help doctors and others understand Travellers' problems better.

Look for themselves to see how we live.

Should come out now and again...medical attention even if people are not ill.

l. **If doctors or nurses did come out to the [caravan] sites, what do you think they could do better on site than at the surgery?**

Almost one third of respondents did not feel that any intervention could be carried out more effectively on the site.

Much the same. If you are near to a clinic, you can go to it.

Immunisations were specified by one quarter of respondents, stressing the role of peer group example or pressure.

Some Travelling people would not go to the doctor, but they would have their needles if they see others have it.

Several respondents thought these visits should primarily be for mothers with their new born babies. Most of the answers were less specific, resembling the answers to 4.4.5.i.

Should come out once a month - check the children. Some women have a harder time...can't get to the doctor.

More time. Talk to the people. Talk freely.

They could explain more to them than in the surgery. People would talk more openly - confident in their own homes.

We could ask questions.

Some Travellers saw visits as the pre-requisite for getting support on environmental issues.

> Maybe a petition by doctors to show how many children get diarrhoea. Health inspectors should come and see the facilities.
>
> See for themselves what conditions we live in.
>
> Help us get a clean place.

m. **If doctors or nurses did come out to the [caravan] sites, what do you think they could do better in their surgery than on site?**

Immunisations were mentioned by three people and examinations in private by a quarter of the respondents.

> The doctors can wash their hands in the surgery. We don't get running water here.

4.4.6 Information about health [23]

a. **Would you like to know more about keeping healthy or how to stop illnesses?**

Over a third of respondents said "No".

> Not really. I would ask the doctor if I needed to know anything.
>
> You know as much as you know. Plenty advertised.
>
> By this time [age] you know all you need to know.

Of the remainder, half said they would but did not specify any particular issues. The other half mentioned a wide range of issues including smoking, weight loss, first aid, pregnancy, healthy eating, arthritis and keeping fit.

> But there's nowhere to find out around here.

b. **Would leaflets be useful? Would reading them be a problem?**

Half the respondents said they would be useful but 16/23 were unable to read themselves. The five people who were non-literate but who thought leaflets would be useful specified that their spouse or child could read it for them.

c. **In what form would you like the information given?**

Table 4.45 Preferred form of health education information

"someone to come round" (8 specified the THV)	11
leaflet	6
talking with doctor in the surgery	4
video	2

> Face-to-face is best, when there's time.

> A medical caravan used to come round. It was a good idea because they gave advice about keeping well [gave example of sister-in-law's son with asthma].

d. **Do you think classes or meeting as a group with the health visitor would be useful?**[15]

One third of interviewees were opposed to groups.

> Not really. Would rather talk with one person.

> Among Travellers, no. Never found it useful to meet like that. We're different to other women. Traveller women are different. People don't like to say too much in front of other people. It's best to talk to the doctor.

Two thirds were in favour of groups to talk about health issues, with half of these respondents specifying women-only groups.

> Yes, but keep it for women only with a woman doctor or...[THV].

> The men would not talk in a group...would not talk in front of women.

> Travellers meeting with settled women [would be a good idea]. Should talk together, then they would understand more about different lives people have.

4.4.7 Immunisations [23]

a. **Do you think immunisations are important?**

Unanimous affirmation.

b. **How are they important?**

About a third of respondents did not give a specific answer to this question.

> Its best to have them.
>
> Makes children secure.

The rest specified the prevention of particular illnesses.

c. **Do you think some immunisations are more important than others? If so which ones?**

Half the interviewees thought some were more important, a quarter thought all were of equal importance and a quarter did not know.

Table 4.46
Immunisations which are more important

Polio	5	Measles	2
Tetanus	5	Mumps	1
Diphtheria	5	Pertussis	1
Rubella	4	"scarlet fever"	1
BCG	4		

d. **Why are these immunisations more important than others?**

Only two Travellers responded to this question. They said those specific illnesses were more dangerous.

e. **Are there some immunisations you would not want your child to have? Which ones?** (not asked of one non-parent)

Two thirds of respondents said there were, all mentioning pertussis and three mentioning measles.

f. **Why?**

All but one of the parents who were opposed to the pertussis vaccine mentioned the risk of brain damage, fits or handicap. Four parents stressed that it was a "normal"

illness. The three parents who were opposed to the measles vaccine also evoked the idea of the "normal" illness. Four respondents said they had obtained information about the dangers of pertussis from the television, three said they knew of children who had suffered brain damage after pertussis immunisation and two felt that Traveller children were especially susceptible to the perceived adverse effects of pertussis vaccine. Two of the parents who were opposed to pertussis immunisation said they did not believe doctors who said it was safe. Three of the parents who said that they approved of all vaccines had in fact not allowed their children to be immunised against pertussis but had subsequently changed their minds:

> Everybody was afraid of the whooping cough needle. I heard it makes them handicapped. Caroline [her daughter] had whooping cough and suffered terrible. I think now I would have the needles done. I blamed myself for not having the others done when I saw the three of them suffer.

Conversely, personal experience led some parents to reject the pertussis vaccine:

> Michael had the needle because he was a weak child. I didn't think he could stand the whooping cough. Afterwards he was unwell and weak for a month. He never had another one.

The refusal to have the pertussis vaccine was not related to the age of the parents and in the interviews we heard both:

> Most Travellers would have the [pertussis] needle now

and

> Young people [parents] don't understand you can get bad effects from the illness.

In many of the interviews Travellers implied that the pertussis and, to a lesser extent, the measles vaccine were not appropriate for their children, while acknowledging their widespread acceptance among settled people. The interviewer was told several times

> *Travellers just don't have them.*

One interviewee implied that susceptibility to brain damage from the pertussis vaccine is more prevalent among Travellers

> It runs in our people. It turns them backwards.

4.4.8 Medical record cards[24]

1. **Have you ever been given a record card like this by a doctor or nurse or health visitor?** [shown medical record card issued in another part of the study]. About half the respondents said they had.[1] Questions 2-4 were directed at them.

2. **Where was the card given to you?**
All but one, which came from Sheffield, were given at one health centre in Hackney.

3. **The last time you saw a doctor or nurse did you give them the card to look at? If not, why not?**
Half the respondents who had seen a doctor since the card was issued had not used it, either because they had forgotten it, lost it or were already "known" to the doctor and therefore felt its use was inappropriate.

> Hospital never gave me my card back.
>
> Thrown out in rubbish...by accident!

4. **If you've never used your card, when would you use it?**

> If I went away to a strange doctor I would take it. My own doctor knows me.
>
> If I went to another doctor.
>
> If I went away on holiday I would use them.

5. **Do you think it would be/is useful to carry your own medical records?**
All 24 of the Travellers who took part in this section of the interview thought that handheld medical cards would be useful *in some circumstances.*
For people who are not educated it would be helpful.

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[1] I know from examination of records from the epidemiological part of this study that another six of the interviewed Travellers had actually been given hand-held record cards for themselves or their children.

> Yes, but a lot can't read or write so when the doctor writes on the cards it doesn't mean anything.
>
> It's a good idea for Travelling people. You can take it to the doctor or hospital in an emergency. It tells them what needles the child has had.
>
> Could get knocked down. Tell what tablets you're on. If you're allergic to anything.
>
> Especially going back home [Ireland].

Five respondents thought that the main value of the card was that it might enable them to be seen by doctors.

> Should be distributed round the country. It would be good if it helped you get seen by doctors who don't know you.
>
> Just make an appointment by showing them that [card]. It would prove you were stopping in the area.

Several respondents felt that the hand-held medical records were only useful if they were actively travelling.

> Not usually, because your doctor keeps your notes. But if you're moving about they are very handy.
>
> If you're travelling its a good idea.

Doubt was expressed about healthy adults using the cards.

> Not for me, but for the children

4.4.9 Smoking alcohol and diet [24]

a. Do you think smoking has any effect on your health?

Two interviewees initially stated that smoking had no health implications ("I've had no problems"), and a third interviewee answered ambiguously:

> The news says it causes cancer.

When pressed for an explicit answer, all interviewees specified some negative consequences of smoking with more than three quarters specifying respiratory

illnesses, a quarter mentioning cancer, a sixth mentioning heart disease and loss of appetite and a few mentioning skin problems, children's health and liver cirrhosis.

> No good for the chest, dries it up. All round does harm to your looks, your hair and body.
>
> Kills you. I hate them. Its bad for your health.
>
> If I had me time back again I would stop. Makes you lazy. Starts a smoker's cough.

b. **In what way do you think it is good for you?**

This additional question was added after the first 6 interviews and was asked before 9.a. Two thirds of respondents denied that smoking could be good in any way. The rest specified "cooling nerves", "taking troubles away" or "giving comfort". These answers did not differ between smokers and non-smokers.

c. **Why do people smoke?**

Half the respondents mentioned "habit or addiction" and a third mentioned "nerves". Peer pressure and boredom were mentioned twice.

> Everyone has their own habits. The only way to stop people smoking is close down the cigarette factories.
>
> Some just like smoking. Its like longing for a cup of tea.
>
> If you feel nervous or really depressed. Most have bad nerves. Helps them cope.
>
> Sometimes really calms me down.
>
> You think it will take your troubles away.

d. **What could be done to help people stop smoking?**

Table 4.47 Support for smoking cessation

up to themselves/will-power	Ban sales/ manufacture	Nothing	Medication	"Nag them"	Do not know
9	4	5	2	1	3

Four fifths of the respondents who said nothing can be done to help smokers stop were smokers.

I'd like to stop, but don't know how

I only have myself to blame.

e. Do you smoke?

This question was asked after the other smoking questions. Half the respondents smoked.

f. **What do you think about drinking alcohol?**

Almost a quarter of the interviewees - all women - said they did not drink.

It made me sick, so I stopped.

Don't like it. Don't do it myself.

More than half the respondents said it was alright in moderation and a quarter said they did not know.

Not drinking at all is good but 2 or 3 pints won't harm you.

OK if you don't let it get into the home.

g. **In what ways do you think drinking can be good for your health?**

Half the respondents felt alcohol had no positive health effects, but this included people who felt moderate drinking was acceptable.

I wouldn't say drinking is *good*, but it's alright every Saturday night, a couple of pints.

Beneficial effects of alcohol were various.

Guiness is good for you. Iron in it. Particularly if you're expecting.

It's good for the brain cells.

They may be a bit shy. Gives false courage. They enjoy themselves.

Good for stress. Relieves a lot of tension.

Port wine and lemonade is a good tonic for the baby.

h. **In what way do you think drinking can be bad for your health?**

A quarter of respondents mentioned liver damage and a quarter mentioned "drunkenness". Alcoholism, family breakup or heart damage were also mentioned. Almost a third could not specify the harm.

> It kills people if you drink too much. A lot of relations in Manchester died of drink.
>
> Effects your brain the next day.
>
> Wrecks the home. Too much burns the liver out. Wreck cars.
>
> Shorts are very bad. Effects the liver.
>
> If you get attached to it, you become an alcoholic, become a different character.
>
> My father drinks for a few days then he's sick and coughs up blood and doesn't eat. Twice it broke my mother with his drinking. It breaks the family.

In the discussion of alcohol we did not ask Travellers to specify "safe limits". To the extent that they spontaneously mentioned quantities it was in terms of "two to three pints are alright on the weekend". One woman said that she saw "posters in the doctors to drink so much as a limit - which frightens you."

i. **Do you think the food you eat has any effect on your health?**

Almost two thirds of respondents thought it did. Asked to specify the health effect, answers dwelt on the adverse effects of certain foods with almost half of respondents who thought food did have an effect on health mentioning "greasy" foods. A couple mentioned the danger of chemicals in food.

> People have their own taste in food. Too much fat smothers the heart up.
>
> Greasy food gives spots, ulcers and is bad for you.
>
> Too much grease is bad. Too many chips - runs round your heart. Then you lose your breath.
>
> Tinned food is no good.

j. Which foods are healthy?

Table 4.48 Healthy foods

vegetables	fruit	salads	boiled food	fresh food
10	9	6	6	4
fish	dairy products	meat	whole meal bread	cornflakes
2	1	1	1	1

Food should not be stored. (three interviewees)

> Over here [England] we need to eat more. Back home food is richer, more goodness. Nothing fills you up here.

> We can't afford to buy the food we would like.

4.4.10 Women's health needs and problems

Only women were asked questions in this section of the interview. Twenty-two women were present for the cervical smear part, although one did not know what a smear was and another had not yet had intercourse and did not want to discuss smears. Only twenty women were present for the pregnancy/postnatal care questions. One woman who had never been pregnant was excluded and another two (one who had a stillbirth) did not want to talk about pregnancy. Therefore the discussion of pregnancy and postnatal care involved only 17 women.

a. Do you know what a cervical smear is? Have you ever had one?

All but one respondent said they did and four fifths said that had a smear. All the respondents who said they knew what a smear was mentioned an internal examination as part of the procedure when asked to describe how a cervical smear was taken if they did not spontaneously say what it was.

b. If you haven't had a cervical smear, why not?

> Not until after the first child is born. Wouldn't have one now. It might harm the baby. [pregnant 18 year old]

> Don't know. Might have one when I get settled. [24 year old with three children]
>
> To tell you the truth, I don't think about it. I've got so many problems I just deal with what I have to at the time. Maybe when I get all the other things sorted out I will have it done. But I just don't get time. [28 year old with 4 children]

c. Do you think smears are important?

A quarter said they were not or that they didn't know.

d. Why are they important?

Under half the women specified cancer and only two mentioned the prevention of cancer. Half mentioned the detection of other diseases, mentioning infections and leukaemia. Three women said while they knew that the smear was an important test, they did not know why.

> Good to check your health.
>
> Nice to have a checkup and have less worry.
>
> Hear a lot of women have womb cancer.
>
> I go along with what the doctors say.

e. Would you be more likely to have a cervical smear if you were seen by a woman doctor or nurse?

Three quarters of women said they would be more likely to have a smear if they knew a women would be performing the procedure.

f. Would you be more likely to have a cervical smear if a medical health trailer/caravan came to the site?

More than two thirds of women were opposed to having smears on the caravan site.

> Rather go to doctor. Would refuse if it was on the site. No privacy. Too embarrassing.
>
> Don't think many Travellers would like that.

Rather have it at the health centre. Wouldn't like to have it done in the caravan at all. None of our women would like that. Wouldn't mind an X-ray in the caravan.

I think a lot would like that instead of in surgery.

g. **Are there any other things which would make it more likely to have a smear done?**

If they described it in a different way.

Not while I'm pregnant.

You should not have a smear done while you are pregnant -it's dangerous. Smears should be done *after* the birth of the baby.[1]

h. **What do you think are the most important things for keeping healthy in pregnancy?**

Table 4.49 Staying healthy in pregnancy

good diet	fruit	antenatal care	fitness/look after yourself	hygiene	good site facilities
7	4	4	3	3	2
iron	rest/sleep	lucozade	vitamins	avoiding ill people	don't know
2	2	2	1	1	1

i. **When you are pregnant, do you feel that anything you do or don't do, during pregnancy may affect the health of your baby?**

No	smoking	drinking	lifting/ accidents	late antenatal booking	medication
2	9	6	2	1	1

[1] This respondent did not want to talk about smears in the context of the formal interview and this comment only emerged during informal discussion once the interviewer put the questionnaire away. The patient explained that she know two women who had lost their babies because they had cervical smears while pregnant.

Six of the nine women who mentioned smoking smoked in their last pregnancy, but none of the six who mentioned drinking drank in their last pregnancy.

The nine women who mentioned smoking were asked:

j. **"Why do you think it is harmful, what can it do?**

Table 4.50 Smoking in pregnancy

low weight	chest problems	jaundice	cancer	don't know
4	3	3	2	1

The 6 women who mentioned alcohol were asked:

k. **"Why do you think it is harmful, what can it do?"**

Three said it can "kill" and three said they did not know.

l. **At what stage of pregnancy (how many months) would you see a doctor?**

Table 4.51 Booking antenatal appointment

TRIMESTER		
First	Second	Third
10	4	3

> First baby never went to the doctor...Second one went at 5 months. Then found out about tests. Now should go straight away.
>
> If I had problems would go early, otherwise wait until 5 months.
>
> Years ago...6 months. Later I went straight away.

This question was asked about the last pregnancy:

m. **Who did you see after the baby's birth?** (asked to specify doctor, midwife and/or health visitor, as well as where and when they were seen).

Only fourteen women answered this question; one who had answered the other

questions in the pregnancy section has yet to complete her first pregnancy. Ten women were seen for the first ten days after birth by a midwife or the Travellers' health visitor on the caravan site. One other women visited the midwife in a clinic because after delivery her caravan had been "moved on". One was in hospital for 14 days following a caesarian section. Two women and their new born babies received no post-natal care. Six women had a post-natal check from a doctor six weeks after delivery and one saw a doctor two weeks after delivery for a blood test.

4.4.11 Environmental facilities

Twenty-three Travellers were available for this section. Five were excluded because they did not live in a caravan. The 18 respondents lived on seven sites in three boroughs:

Table 4.52 Environmental facilities

Place	Cara vans	water	hot water	electric	rubbish collect	toilets	post
HACKNEY							
Prout Rd.[1]	8	no	no	gener	once (in 6/12)	no	no
Ash Grove[2]	17	no	no	gener	no	no	no
Gransden Avenue[3]	12	site*	no	mains	yes	yes	yes
HARINGEY							
Wood Green[4]	15	yes	yes	mains	yes	yes	site*
Ferry Lane[5]	6-8	site*	no	no	site*	yes	no
TOWER HAMLETS							
Eleanor St[6]	15	yes	yes	mains	yes	yes	yes
Eleanor St[7]	4	no	no	gener	no	no	no

* communal supply

When water was not available Travellers would obtain water from a local garage, factory or friends on a permanent site. These sources were up to a mile away from their site.

---

[1] illegal temporary site off the Leabridge roundabout

[2] illegal temporary site on waste ground off Mare Street

[3] "tolerated" site off London Fields in area of light industry

[4] official site in Haringey

[5] Temporary tolerated site.

[6] official site in Bow

[7] unofficial site on the road side, next to official Eleanor Road site

> We get water from the garage. They don't like it. Sometimes have to pay.

When toilets were not available, public toilets - when available were used - but children mostly used the site. This created friction with neighbours, such as a local pub next to the Prout Rd. site.

> Public toilets close early.

> Have tried to get chemical toilet from council but won't let you even if you're prepared to pay.

Table 4.53 Perceptions of sites' cleanliness and safety for children

SITE	CLEANLINESS	SAFETY FOR CHILDREN
Prout Road	good	moderate
Ash Grove	poor	poor
Gransden Avenue	good	good
Wood Green	good	good
Ferry Lane	good	poor
Eleanor Street (official)	good	poor
Eleanor Street (illegal)	poor	poor

One interviewee said that the cleanliness of his site was poor:

> Not hygienic because the council doesn't empty toilets or bins except when they feel like it.

Blame for rubbish was not only ascribed to the council. On the Ash Grove site other Travellers were criticised for fly-tipping on the site and extraction of metal (eg. copper) which caused fumes. On the Ash Grove site one respondent said:

> There's a lot of rubbish. Should be took away. The children can pick up germs. It's depressing to look at.

Concern for childrens' safety also focused on traffic next to the site, which is why the Ferry Lane and the official Eleanor St. sites were considered unsafe.

Additional comments included satisfaction with the facilities and a desire to stay on the Gransden Avenue and Wood Green sites. The Travellers on the Prout Road site, who had already received a court order to move when we carried out the interviews, also wanted to stay, particularly if the council would provide a skip and toilets.

> The main problem is to be left here. There's no traffic, no one bothers us, we're hidden here. Safe for the children. It's very convenient. The chapel is beside us and the clinic is down the road.

Only one respondent living in a caravan said she would rather live in a flat.The interviewer also asked the five flat/house dwellers for any comments about how they were living.

> Great to have facilities. But the neighbours are not used to Traveller kids. They're more wild, used to the outdoors. So the neighbours complain and try to get you moved.
>
> At first we didn't like not being in a trailer but we got used to it. Now we want a house - we like it here but it's a squat...I hope we can stay here until after Christmas.
>
> When I lived in a trailer we had everything - would rather live in a trailer.

CHAPTER FIVE: ANALYSIS

The study reported in this dissertation grew out of questions about Traveller health care needs and their access to primary health care services in Hackney, East London. The literature on Traveller-Gypsy health and health care in the British Isles was patchy and of uncertain relevance to the community of Travellers I encountered as a general practitioner. Planning health care for Travellers within general practice or designing appropriate services at health authority level with public health colleagues was impossible without an assessment of Traveller needs and access to services.

The virtual absence of health or health care information for Travellers in London prompted adoption of a broad-based approach to data collection covering a number of health care issues. I used some methods which had not been applied in any study of Travellers to date. The high mobility of Travellers in Hackney and the large resources I would have needed to collect any health status information in a community study led me to base the epidemiological arm of the study in primary care services: two general practices and a paediatric accident and emergency department. This data then informed the in-depth interviews with a smaller sample of Traveller adults. To complement the views of Travellers themselves about the services they received I carried out a short survey of all general practices in East London and collaborated in an analysis of the work of the local Travellers' health visitor (THV).

In spite of methodological difficulties encountered at various stages of the study, I am able to draw some new conclusions about Traveller health care. As a whole this multi-layered locally-based research supports my thesis that focusing on Travellers as an ethnic minority reveals unmet needs and helps to define appropriate methods of health care delivery for this group.

This chapter is largely structured by the nine questions I posed at the end of the review chapter which specifically test my thesis. Results from the three parts of the study are discussed together under the appropriate heading, such as "cardiovascular risk " or "hand-held medical records". But before embarking on the topic-based

discussion, I need to address general methodological problems arising from different parts of the study. Articulating these problems is essential for understanding the limits and validity of my data.

5.1 General discussion of methods

5.1.1 Study of health care providers

General Practice Questionnaire

The initial response rate to the questionnaire posted to all practices in East London (47/103) was poor. On that basis I would have been unable to draw any conclusion about the overall use of general practices by Travellers and information about attitudes would have been from a self-selected group of practitioners. This would have repeated the bias in Linthwaite's (1983) survey. The final response rate, after telephone follow up of non-responders (100/103), was excellent. Not surprisingly, a lower proportion of initial non-responders (6/53) than initial responders (19/47) had seen Travellers in the past month. The almost complete coverage of practices does not permit extrapolation of the findings to individual general practitioners. The questionnaires were addressed to the senior partner who was asked to complete it or pass it on to a colleague where appropriate. Fifty eight percent were completed by another partner. I cannot assume that doctors' views of Travellers are homogenous in a practice, so by not sending a questionnaire to every general practitioner in Hackney I am in effect taking a self-selected sample of doctors within practices. On the other hand decisions in practices about whether to register Travellers or see them at all would probably need the agreement of all the partners. I have already noted the potential conflict between the aim of identifying practices who might participate in health data collection and the aim of characterising general practitioner attitudes. I did not offer general practitioners an anonymous vehicle for expressing their views about Travellers, which may have resulted in a degree of self-censorship. I did not expect any damning revelations and was therefore surprised that ten percent of the sample said they would not accept Travellers as temporary residents.

I chose to limit the length of the questionnaire to a single page to maximise the chances of getting a response, recognising that this left a crude tool for assessing views of practitioners. If resources had allowed, follow-up interviews with doctors could have helped to elucidate their perception of Travellers, but I prioritised in-depth interviews with Travellers themselves.

Community Medical Officer questionnaire

A modified questionnaire was also sent to the nine community medical officers who ran the child health clinics in City and Hackney Health Authority to roughly measure use of these clinics by Traveller parents and to characterise how Travellers are viewed by these doctors. All nine returned the questionnaire after telephone prompting.

Review of the Travellers' Health Visitor Role

Traveller health visitors (THV) are often cited as the key to health care provision in districts with Traveller patients (Durward 1990). Although there are several reports of their work in the health visiting and nursing literature, there has been no evaluation of their work loads or discussion of priority setting. I anticipated that my study of Traveller health care needs and interviews with Travellers would result in a re-thinking of priorities which would invariably involve the local THV. Therefore it was important to assess her role and work load. Even before I had the results of data collection in the practices and the accident and emergency department, it was clear that the THV was feeling overwhelmed by her job which led her to request help in analyzing her role and formulating recommendations to the District Health Authority. The three parts of this survey consisted of a description of her multiple tasks which arose out of discussions with the THV, a three-month retrospective analysis of routine weekly returns of workload and a two-week prospective analysis using a specially designed log.

The first part provided a qualitative view of the THV's work as she perceived it, which was revealing in its own right and also helped inform the design of a log which allowed collection of semi-quantitative data. The second part of the survey

retrospectively analysed the THV's work log over three months. This log contained routine client and colleague contact data and gave a rough guide to different kinds of work. Because of the specialist and wide-ranging nature of the THV role, it inadequately reflected her work. Therefore in the third part of the survey we collected data from a more detailed log which the THV kept for two weeks.

The main problem with this survey was that the retrospective log was insufficiently detailed, but the THV was only willing to use the more detailed and specific log for two weeks. The comparison with routinely collected data from Bloomsbury health visitors is arbitrary. Since the method of recording was not standardised, a true comparison of workload is not possible. The two weeks of prospective data collection may not have been representative of the THV's workload over a longer period and therefore the quantifiable aspect of this log was potentially misleading. There is an inverse relation between the amount of information about work load a subject can collect and the period of time one can realistically expect her to collect it, particularly in a job which has many different components and loci.

5.1.2 Descriptive epidemiology from primary care

The sample

Despite identifying seven practices in East London who reported more than one Traveller patient per week, I ultimately only had the cooperation of two practices (a total of 12 doctors) for data collection. The five which dropped out at the discussion phase were concerned that collecting data on consecutive Traveller patients and giving out hand-held record cards would generate too much extra work. Several practices pointed out that the majority of Traveller patients came without appointments, often near the end of a surgery, when doctors feel most pressurised. Involving general practitioners in data collection is always a challenge in primary care research (Murphy and others 1992) and even after agreement to participate, studies have collapsed when doctors fail to recruit patients (Tognoni and others 1991). One consequence of data collection being restricted to 12 doctors was a longer study time

to obtain a reasonable sample size.

Another consequence of ultimately only recruiting two practices into the study was a high degree of self-selection. Essentially I was left with practices which were committed to improving care for Traveller patients. As one of the issues I addressed was provision of cervical smears and immunisations, data collection in these practices probably gave a "best case" result.

When considering uptake of preventive health care the Traveller sample was a "best case" in another sense: it is likely that general practice attenders were not representative of Travellers as a whole and were more likely to have access to cervical smears and immunisations. In the case of children I tried to test this assumption by comparing immunisation rates of practice and Queen Elizabeth Hospital-recruited cases.

As discussed in the introduction, there were no legal caravan sites in Hackney and many Traveller families moved between illegal sites and temporary accommodation, usually squatting. In order not to exclude from the study Travellers who gave a house address I included patients whose notes contained a previous caravan site address or were known to be part of a Traveller family by receptionists in the practice or nurses in Queen Elizabeth Hospital. In my regular meetings with the receptionists and nurses recruiting patients into the study I found that this did not create ambiguity in the identification of patients eligible for recruitment. If a non-Traveller patient was accidentally approached for inclusion, when the nature of the study was explained I assumed that they would point out the mis-identification. This approach to ethnic group identification, using self-ascription as the final arbiter, is congruent with the approach to ethnicity I define in the chapter one. The recruitment criteria exclude Travellers who gave a house address *and* were new to the practice or Queen Elizabeth Hospital.

Age-sex matched controls came from the heterogenous settled population served by the two practices and Queen Elizabeth accident and emergency department. As

discussed in my literature review, this population is multi-ethnic and has a high proportion of low income and single parent families (City and Hackney Health Authority 1990). Compared to other areas of the United Kingdom, a large proportion of the population is highly mobile, with the two participating practices recording a 25-30% annual turnover of patients. Neither of the practices nor the accident and emergency department routinely recorded the ethnic identity or social class of patients and were reluctant to record this information for the control patients in the study. After discussion at the pilot stage, I did not include ethnic group or social class as variables in the final data card.

I aimed to recruit consecutive Travellers who presented in the practices and in the accident and emergency department. In the practices 72% of Traveller children were recruited into the study, whereas at Queen Elizabeth only 44% were recruited. Seventy five percent of Traveller women and 49% of Traveller men were recruited in the practices. The low rate of recruitment of Traveller children attending the accident and emergency department was due to the large number of staff who were asked to recruit and the presentation of many Traveller children at times of peak activity in the department. It was not due to parental refusal to give information. The high rate of control recruitment is a function of the method used: I asked nurses to recruit the next two non-Traveller children who were seen in the department (ie. whose name appeared in the register). If a nurse was willing to recruit a Traveller child, she was more likely to recruit the controls.

The low recruitment rate for Traveller men compared to women was probably due to a higher proportion of men refusing to enter the study at all. In the practices, settled children or adults only had a chance to be recruited if they presented to the doctors during the study period. The low recruitment rate was due to a combination of controls not presenting for medical care during the study period and receptionists or doctors not asking them to join the study.

Age/sex structure

In both the practices and the accident and emergency department the group of non-

recruited Travellers had similar age/sex distributions to the recruited samples, which excluded a systematic age/sex bias. It does not exclude other systematic biases. For instance it is possible that Travellers who presented without appointments, particularly towards the end of surgeries, were less likely to be recruited and might have other characteristics which distinguished them from the study population.

Seventy percent of the potential controls in the practices and 80% in the accident and emergency department were recruited. Not all potential controls consulted the practices during the study period and controls presenting after Travellers in the accident and emergency department were not always recruited. The age-sex distribution of the adult control sample was similar to the Traveller sample, allowing comparison of alcohol consumption, cervical smear rates and cardiovascular risk factors, although the preponderance of young adults in the sample limited the power of the serum cholesterol, serum glucose and blood pressure analysis. In the sample of children, those under two years of age constituted 45% of the Traveller and only 38% of the control sample. Conversely, children aged 2 to 3 years constituted 26% of the control but only 20% of the Traveller sample. Analysis of birthweight and immunisation status was relatively unaffected by this difference in age structure of the Traveller and control samples, as the birthweight is independent of age and immunisation status is corrected for age. A potential problem though was the effect of age on accuracy of parental recall. This was not a problem if the parent said he or she could not remember the information, but was if they mis-remembered. In the case of immunisation status, where one needs to recall several pieces of information, I only included data on children under seven years of age. In the case of birthweight I controlled for erroneous recollection in older children by analyzing the total sample as well as children under seven years old.

Unreliability of reported place of residence

In the Irish mortality study (Barry and others 1989) data from Travellers living in houses and on caravan sites were compared. In my study I also collected information about Travellers' addresses. I intended a sub-group analysis on some of the variables such as immunisation and cervical smear uptake to determine if these were influenced

by type of accommodation (fixed dwelling or caravan) and area. Once the study was under way it became clear that this type of analysis would be worthless. I reviewed addresses which Travellers gave the practices and the accident and emergency department with the Travellers' health visitor. Of the Travellers known to the THV at least one third of the addresses did not correspond to where the patient was actually staying at the time they were recruited into the study. Some Travellers assumed that if they were staying outside of Hackney they could not be seen in the practices and therefore gave a fictitious Hackney address. This was encouraged by some doctors and receptionists who were aware that an address outside the family health service authority on a temporary resident form would render the claim invalid. Other Travellers thought that if they gave the address of their caravan site, rather than that of a house, they might not be seen. Others who were squatting (illegally) did not want to reveal this information and therefore said they were on a caravan site. In their contact with the settled community and particularly with institutions which wield power over their lives Travellers will choose to present information about themselves which maximises their access to these institutions (Adams and others 1975). General practices are no exception to this principle.

5.1.3 Interviews with Travellers

My review of previous research did not uncover any studies of Travellers' views of health services. Nor had any researcher explored beliefs of Travellers about illness causation and prevention, although Okely's (1983) detailed work on symbolic boundaries revealed aspects of Traveller culture with implications for health care and relations between health professionals and Travellers.

My experience of three unstructured interviews with Travellers suggested that detailed views about health and illness could be explored qualitatively. But in a totally unstructured interview I might lose the opportunity to systematically enquire about issues raised by the epidemiological part of my study: low cervical smear and immunisation rates and a high smoking rate. My ignorance about Traveller mobility, the acceptability of hand-held record cards and their access to primary care also

required some form of systematic enquiry to inform service planning. Questions about environmental conditions on sites were suggested by Travellers themselves. Therefore I chose a semi-structured interview format, "guided" by a questionnaire but also recording comments which expanded on or even diverged from the questions.

The wide range of responses for most of the questions and the loss of information which would have resulted from a limited set of responses led me to group the responses after the interviews rather than pre-code them. Although I have grouped responses into categories for analysis, my understanding of Travellers' views was also based on the commentary which Travellers provided around the questions, some of which I have reported in the results section. Despite these efforts to "open" the interview, the questionnaire format often felt awkward and made some Travellers uncomfortable (see footnote 1, p.112).

Okely has criticised the questionnaire/one-off interview method as applied to Travellers:

> It was proposed that I administer a massive questionnaire before moving on, rather like a mobile X-ray unit, to the next camp... The gypsies proved brilliantly inconsistent. It was recognised that their answers could not be 'coded'...much of the information in the questionnaire could be obtained informally and single stranded answers to questions of opinion were not only unreliable but also simplistic and dubious (1983:39).

In my study the views of Travellers about health and health care were constrained by the structure of the questionnaire - despite its relatively open design - and the assumptions from the medical model on which most of the questions are based.
There are two other reasons why the results need to be treated with caution. First, the interviewees were not a representative sample of Travellers either living in Hackney or using a Hackney health centre. I did not know the views of Travellers who declined to be interviewed or ignored the interviewer knocking at the door of their caravan. This group, like non-responders in other studies (Eliott 1991), may well have different views about health and health care than those agreeing to be interviewed . Second, the different contexts of the interviews and the other people present may have substantially affected the responses.

Nevertheless, concurrent with a more limited questionnaire-based survey of 25 Traveller women in County Wicklow (O'Byrne 1990), this was the first survey of Travellers' views on health and health care. Beyond any specific findings from the interviews, this part of my study showed that interviewing Travellers about health and health care was feasible and tested a series of questions which most Travellers were willing to discuss. All of the interviewed Travellers were either also recruited in the epidemiological part of the study or had children who were. In effect they were a (non-random) sub-sample of the larger group from which I collected epidemiological data. Therefore it is legitimate to discuss the interview findings in relation to data from the other arms of the study.

5.2 Birthweight and growth of Traveller children

5.2.1 Birthweight

There was no difference between Travellers and controls in the proportion of low birth weight babies in my sample. Both reported a higher rate of babies weighing less than 2.5 kilos at birth than the national rate in 1988. But the proportion of low birth weights among Travellers (7.5%) was less than the rate found among Travellers in Kent (Pahl and Vaile 1986) and that recorded in Hackney in 1988 (9.3%). The proportion of low birthweight babies in Hackney is the third highest among all health districts in England and largely reflects the high socio-economic deprivation of local families (City and Hackney Health Authority 1992). The difference between my control sample and the recorded low birthweight rate for Hackney may reflect bias in my sample compared to the total population of settled children.

The sample of Traveller children had a significantly higher mean birthweight and higher proportion of children with a birthweight greater than four kilos than the control group. This was probably due to the large family size of Travellers in East London: in my interview sample the mean number of children per family was 4.5. Birthweight is least in the first born and tends to rise with each birth thereafter (Alberman 1991). Without data on birth order, I could not correct for this factor and therefore cannot rule out another explanation, such as an increased rate of impaired

glucose tolerance in pregnant Travellers. The only direct clinical significance of high birth weight is that the mortality rate for babies rises slightly if the weight is greater than four kilos (Alberman 1991).

A possible weakness of the birthweight result was the accuracy of parental recall but the result was the same when a subgroup of younger children was analyzed, where parental recall is less problematic. The source of the birthweight data -parental recall- was the same as in the other two studies of birthweight of Traveller children (Linthwaite 1983, Pahl and Vaile 1986), but in a sample of primary care attenders rather than from a community survey. Either the prevalence of low birth weight babies is higher in the total Traveller population in Hackney or the difference in birthweights between different Traveller groups is real.

This highlights a point which repeatedly emerges from my study: Travellers are not a homogenous group nationally or even regionally and local research is required to articulate their health needs. Generalisations about Traveller health status or use of services are as misleading as those about Traveller culture:

> The differences between the conclusions of these [anthropological and sociological] studies serve as a valuable reminder of the heterogeneity of Gypsy culture. The great fault of the literature on Gypsies, both official and academic is over-generalisation; observers have too easily been led to believe that the practices of particular groups are universal...(Acton 1974a:3).

5.2.2 Growth

This component of the study was restricted to the Queen Elizabeth sample because the participating general practitioners were not willing to measure weights or heights of children presenting to them. The sample size was further reduced since over a quarter of children recruited at Queen Elizabeth were not weighed. I was not able to convince "frontline" staff to consistently perform procedures which they did not routinely do. I did not find a significant difference between the Traveller and control samples in proportion of children less than or equal to the third centile in weight but - because of the small sample size - the data was consistent with 13.5% more

Traveller than control children below the third centile or 11% more control than Traveller children below the third centile. Both groups had a higher proportion than expected of children below the third centile in weight (Travellers 9.1% and settled children 7.8%). I have not replicated the findings of the Creedon (1975) study in Dublin showing a consistent deficit in weight among Travellers compared to settled children. On the other hand, failure to collect data on height, as well as the small sample size stops me drawing any conclusions about growth of Traveller children in Hackney.

From the survey of community medical officers and the immunisation uptake data I know that the majority of Traveller children in my sample did not attend child health clinics. Traveller parents used primary care for acute health problems in their children and it is likely that many of their children had not had developmental checks after the first year of life. The low rate of school attendance for Traveller children in Hackney (p.33) meant they would also miss their five-year check which is organised by the school nurse. Therefore even if Traveller children had the same rate of growth problems as settled children there is less chance they would be detected.

I was unable to convince even enthusiastic general practitioners to record the height and weight of Traveller children presenting outside the context of child health clinics over a limited period of time. Therefore general practice is the not best place to monitor the growth of Traveller children. Until attendance in child health clinics and school becomes the norm for Traveller children in Hackney, the only means to monitor growth is the Travellers' health visitor on her visits to sites.

There is still a lack of evidence that growth monitoring in children is a valid screening method. In the case of weight, the joint working party on child health surveillance was

> ...not convinced that the advantages conferred by regular weighing justify the resources required or the anxiety generated by inexpert interpretation of growth charts (Hall 1992:47).

Although the working party recommended that one height measurement is taken

around three years of age and another between four and five, Hall comments that there is still no convincing evidence for routine height monitoring. A recent study in Wessex has shifted the debate towards height screening by showing that a remediable disease can be newly diagnosed in 1 in 3-4000 school children by investigating all very short children (Voss and others 1992). If height screening is desirable, then even without showing that Traveller children are at greater risk of growth retardation, an outreach screening service will be required.

5.3 Immunisation

The immunisation component of this study had three parts:

- parental reports of immunisations followed by partial validation from the district database and manual records.
- assay of serum from adult Travellers and controls for polio antibodies.
- questionnaire-guided interviews with Traveller parents on attitudes towards immunisations.

Several parts of the questionnaire were relevant to immunisations: prevention of childhood illnesses (4.4.4), possible work of medical staff on caravan sites (4.4.5), specific questions about immunisation views (4.4.7).

5.3.1 Immunisation rates

The completion rate for the primary course was very low, even when compared to an inner city control population. Although the completion rate for the double antigen and polio was higher than in other studies of Traveller children, that for pertussis and measles was dismal. Two thirds of the Traveller sample were children attending a general practice; they may not be representative of Traveller children as a whole living in Hackney. As a sample of the total Traveller population in Hackney, their use of general practice services probably biases the results towards an *overestimate* of immunisation rates.

Is it possible that the low rates were due to under-reporting? As both parental recall and district child health record systems may be unreliable there was some uncertainty

about my data. Nevertheless, concordance between parental and other reports was good, so it is unlikely that the low rates were artefactual. Validation of parental reports was incomplete for Traveller children and for control children seen in the accident and emergency department. Those cases and controls I was able to check suggested no systematic bias. However, one cannot assume that other records, including the district database, constitute a "gold standard" for immunisation status against which parental recall can be judged (Scott 1990). In particular, I may have missed under-reporting by parents in the accident and emergency department if their children were immunised in several districts or even regions. Data may not even have been recorded because the children were seen as "temporary residents" by general practitioners. On the other hand, it is equally likely that parental recall exaggerated the immunisation rate for Traveller children in the accident and emergency department, which may have masked a larger difference in immunisation rates between Traveller and controls.

Immunisation rates, even when (partly) validated, must not be over-interpreted, but scrutiny of this data generates an important hypothesis about the underlying reasons for the low uptake in the Traveller community. About 60% of the Traveller sample had the first double antigen and polio vaccines, but only half completed the course. This "fall off" suggests a problem of access to immunisation services. A 60% completion rate, excluding pertussis, might be a *minimum* level that could be reached simply by improving access. It is unlikely that more than a small number of children would have been consciously withdrawn from the primary course by their parents after the first immunisation. The uptake of the second double antigen and polio is 45%, halfway between the first and the third. Analysis of completed primary courses by age of the child which shows continuing uptake of the diphtheria and tetanus vaccines throughout the age range studied, a pattern one would expect if access to immunisation services was a problem for Travellers. In contrast Traveller pertussis uptake does not increase with age, implying that factors other than access may be important.

5.3.2 Polio immunity

The high immunity to polio in young Traveller adults, which was not significantly different from the control population, is reassuring. It confirms the only other study of Traveller immunity, carried out among Scottish Travellers in 1981 which detected the presence of all three polio antibodies in 84% of the sample, from a population which also had a low reported polio immunisation rate : less than 50% (Riding 1985). The Scottish study is not strictly comparable to mine, since it was community-based with blood drawn on caravan sites. In my study it is unlikely that Traveller adults would have a higher immunisation rate than the current generation of children, so the most plausible explanation for the high level of immunity is infection with vaccina or wild-type polio virus.

After immunisation with the oral polio vaccine, faecal viral shedding is a well-recognised mechanism for vaccina transmission. This is not without risk, since the attenuated vaccine may revert to neurovirulence in the gut, creating a risk of paralytic polio infection to anyone in direct contact with the faeces, particularly if they are unimmunised (Beale 1990). This risk is not present with the inactivated polio vaccine. On the other hand, in a partially immunised community like the Travellers, there is a strong case for the oral vaccine because of potentially increased herd immunity from stimulation of mucosal immunity to the wild virus, displacement of the wild virus in the community and immunisation of contacts. The desirability of replacing the attenuated with a killed polio vaccine is currently being debated (Beale 1990). The significant immunity among Travellers in Hackney and in Scotland, although I cannot distinguish wild type and vaccine-based immunity, is a concrete example of herd immunity which supports the argument in favour of retaining the oral vaccine in the United Kingdom.

> If inactivated vaccine completely replaced the oral form...circulating viruses would gradually disappear...so that pockets of unprotected children might come to be formed (Chamberlain 1987:159).

Evidence in support of this concern recently came from two cases of Type 3 poliovirus infection in Holland. Both patients were part of reclusive groups who decline vaccination on religious grounds (Spanger 1992).

Nevertheless, despite high adult immunity, Travellers in the United Kingdom are at greater risk of sporadic paralytic poliomyelitis than the settled population (Begg and others 1987). This points to the limits of passive immunisation among Travellers and the need to increase immunisation rates. Outbreaks of poliomyelitis are particularly dangerous in communities with a high population density (Acheson 1989) and where there is exposure to contaminated sewage, which has been reported on Traveller caravan sites (Sirockin 1988). In a poliomyelitis outbreak in Israel in 1988, in one quarter of the 15 cases there was evidence of direct and long-term exposure to contaminated sewage (Slater and others 1990). Despite low immunization rates, Travellers may not be among the highest risk groups for poliomyelitis infection. A study on a Glasgow housing estate where there was an outbreak of hepatitis A from sewage contamination of the water supply found that one third of the sera examined for hepatitis A lacked Type 3 poliovirus antibodies (Cameron and others 1993).

I did not have the resources to assess immunity to the other components of the primary course of immunisations, although I would expect a high proportion of adults to be immune to measles and pertussis through childhood infection. Unfortunately, even if this were the case, it does not address the main risk of measles and pertussis complications which is predominantly to infants (Rudd 1991). It would be unethical to assess childhood immunity, unless serum was used from blood that was taken for clinical indications (Morgan-Capner and others 1988).

Measles, pertussis and diphtheria are notifiable diseases. Unfortunately the reliability of notification statistics is questionable because of general practitioners' ignorance about which diseases should be notified and their lack of application in sending in notification forms.* As a method of assessing the prevalence of these illnesses among Travellers it is even less reliable because a child with these illnesses is probably less likely to see a general practitioner.

Nevertheless I analysed returns to the Hackney environmental health department on the assumption that I could at least detect "epidemics" of pertussis, measles and diphtheria. My criterion for identifying Travellers was a caravan site address, which

*(Heap 1992)

Travellers living in houses. In the period 1985-1992, there was only one notified case of diphtheria (not in a Traveller), 459 notified measles cases and 244 notified pertussis cases. Two percent of the pertussis and measles cases were in Traveller children, which does not support a hypothesis that these illnesses are disproportionate problems in the Traveller community. On the other hand, my data on completion rates and anecdotal reports of measles and pertussis clusters on caravan sites provide ample justification for targeting childhood immunisation as a priority in Traveller health care. In May 1993, nine cases of measles were reported on one caravan site (City and Hackney Dept of Public Health, personal communication). As in the United States where unimmunised African-American and Latino children experience outbreaks of measles even with a national immunisation rate of 98% (Charatan 1991), Traveller children remain vulnerable to measles and pertussis although national immunisation rates continue to rise.

There is little research on the differential uptake of immunisations by ethnic groups. A notable exception is the survey by Baker and others (1984) in Bradford showing a *higher* completion rate by children of Indian, Pakistani and Bengaldeshi origin compared to "British"(sic) children. The highest non-completion rate was in the "half-negro"(sic) group. Even in this group, completion of the double antigen course and pertussis course was 64.5% and 29% respectively, considerably better than any survey of Traveller immunisation. The interpretation of immunization rates by ethnic group can be misleading, as family size (Li and Taylor 1993) and socioeconomic status (Bennett and Smith 1992) are independently correlated with lower completion rates.

5.3.3 Parental views

Parental attitudes towards immunisations, which the National Immunisation Study (Peckham and others 1989) highlighted as the most important factor in low immunisation rates, may be only one of several factors accounting for the low rate among Travellers, including poor access to services and mobility. These are usually not problems for the majority community, although they are for homeless families in

bed and breakfast accommodation (Conway 1988). Only 23% of Traveller children had their first pertussis and 20% their measles/MMR immunisations, which suggests a larger role for parental choice with these vaccines. This was confirmed in parental interviews, where pertussis and measles were considered "normal" illnesses for children, different from diphtheria, tetanus and polio. A quarter of the interviewed parents mentioned whooping cough and measles among the "main illnesses" which their children get (4.4.4d), only outranked by gastroenteritis and respiratory illnesses. In a general discussion of how to prevent "main illnesses" (4.4.4f), a quarter of parents mentioned immunisations, but mostly in relation to polio and tetanus.

In O'Byrne's (1990) study, she asked a general question to mothers whose children had not started or not completed immunisations (20/25). Five "were vehement in their opposition to immunisation", but the reasons were not explored by the interviewer. Eight gave the reason that their children were too "chesty" to complete the primary course and another five professed "apathy [sic] or inconvenience". O'Byrne does not present data on the differential uptake of components of the primary course nor does she probe further into parental responses to her questions about immunisations. O'Byrne does give us an insight into the problems she faced discussing immunisation with Travellers:

> The knowledge of immunisation names and the protection offered was not forthcoming. In order to avoid discomfort and also getting an answer simply for the sake of an answer I did not dwell on these questions, but noted the answer given (1990:35).

In my study respondents' knowledge of immunisation names was also incomplete, but most of the interviewed Travellers were not discomfited by further exploration of immunisation issues.

In addition to any views Traveller parents might have about the "normal" nature of pertussis and measles, most of my respondents feared the pertussis vaccine. While other ethnic minorities may have been shielded from the effects of adverse media publicity by language barriers (Bhopal and Samin 1988), television programmes on the putative dangers of pertussis vaccine may have reinforced long held concerns of Travellers about the dangers of immunisations. The belief that the pertussis vaccine

carries a serious risk of fits and brain damage is now held more tenaciously by Travellers than by the settled community. Although the settled population also has concerns about the safety of the pertussis vaccine - 70% of parents in one Welsh study were worried or extremely worried about it (Barlow & Walker 1990) - this concern seems to result in a much higher rate of vaccine refusal among Travellers.

It is possible that rejection of the pertussis (and perhaps the measles/MMR) vaccines has become part of the symbolic boundary distinguishing Traveller and settled people. As discussed in section 2.1.5, this consists of pollution taboos and other beliefs which allow Travellers to define themselves as separate and different from the dominant society. Several Travellers in this study, when pressed as to why they did not want their children to have the pertussis vaccine (4.4.7f) made reference to Travellers as a group not wanting them. But is the discrepancy between uptake of pertussis and the other components of the primary course a function of cultural marginalisation in general, rather than specific to Travellers? The Bradford study (Baker and others 1984) in which some ethnic minorities had higher completion rates than the majority population, undermines any simple model of this kind. We need to understand more about the cultural context of beliefs about immunisation, which requires in-depth interviewing and observation during immunization sessions.

Traveller resistance to the pertussis vaccine may be more deeply engrained than their views about the measles or MMR vaccine. Although all the immunisation studies reviewed before starting my study showed an equally low measles uptake, a survey (Gordon and others 1991) of 350 Traveller children in Northern Ireland found a 66% uptake of the measles or MMR vaccinee, which exceeded completion of double antigen and polio course (57%). This was also Mackenzie's experience in a Bradford child health clinic (Mackenzie, personal communication). There is a secular trend in the general population for an increased MMR uptake (Begg and Handford 1989). Despite the same secular trend for an increased uptake of pertussis vaccine, this is not reflected in the Northern Ireland survey where only 36% of Traveller children had their first pertussis immunisation.

If resistance to pertussis has become a cultural barrier, the development of Traveller-oriented health education material in collaboration with parents who have accepted these immunisations, as has been done with the settled population, (Mcguire 1990) is a possible way forward. To date there is no appropriate material from the Health Education Authority despite its commitment to ethnic minority needs. The low literacy rate among Travellers interviewed in my study, which corresponds to low rates found in most Gypsy-Traveller populations throughout Europe (Liegois 1987), suggests that exclusive reliance on written health education materials will have a negligible impact. It is likely that health education literature produced to reassure parents about the safety of the pertussis vaccine has largely bypassed the Traveller community. Whereas videos have proved useful with other ethnic minorities (McAvoy & Raza 1991), my study suggests a lack of interest in this medium as a source of health education. In the Hackney study, Travellers expressed a preference for personal health education on caravan sites. There was also an interest in group discussion as a context for health education among women we interviewed.

It is important to find an appropriate medium for Traveller health education, but in our enthusiasm to give immunisations we must not lose sight of the right of a parent to refuse specific vaccines for their child. Travellers' mistrust of doctors will only grow if they are bullied over immunisations. Refusal to have a child immunised may be a rational choice for an individual parent (Brock & Wartman 1990, Nokes & Anderson 1988), although not in the interests of Travellers as a group or society at large. The debate about compulsory immunisations is still active. Anderson and May (1990) put the epidemiological case in favour of this measure and this is echoed by some general practitioners (King 1991). Ironically, compulsory immunisations as a condition of school entry, the system currently used in the United States, would both be ineffective for a community where only a minority of children go to school (Liegois 1987) and might act as a disincentive to Traveller parents to send their children to school.

5.3.4 Health services and Traveller immunisation

The survey of the Hackney Travellers' health visitor's work found that bringing immunisation services onto caravan sites was not a current priority and only happened sporadically. No other agency took on this role. This was a conscious change in policy from the previous post-holder who judged that

> ...whenever possible my work with the families [including immunisation] is done at the site as this has proved the most effective way to deliver services (Lawrie 1983:26).

It is impossible to judge the effectiveness of Lawrie's strategy as no systematic data was collected. At present we know that immunisation rates are unacceptably low and therefore the strategy of providing immunisations to Travellers primarily in health care facilities needs to be re-considered. I think that an immunisation service, particularly for temporary sites, needs to be developed. Parents on more permanent sites should still be encouraged to bring their children for immunisation and other preventive health care to general practice surgeries, as well as general practice and health authority child health clinics.

Cross-authority recording of the immunisation status of Traveller children and the use of hand-held record cards are needed to supplement parental recall. Opportunistic immunisations of siblings who invariably accompany an ill child are an important means of furthering the primary and pre-school courses within surgeries and accident and emergency departments. In Hackney, an "immunisation room" at the Queen Elizabeth Hospital for children would benefit Traveller and settled children who were overdue for immunisations. This strategy has proved successful in the developing world. For example, 84% of eligible children were immunised at a diarrhoeal disease centre in Bangladesh (Kofoed and others 1990).

Less than a fifth of parents of Traveller children recruited in the accident and emergency department were able to give a practice or general practitioner's name, suggesting that this group use general practice services less than children recruited in the two practices. It is therefore likely that a relatively high proportion of Travellers seen in the department were using it as a main source of primary care, as has been

reported for homeless families (Victor and others 1989, Davison and others 1983). It is disappointing that there was no significant difference in immunization uptake between Traveller children recruited in the practices and in the accident and emergency department (QEH). The practices had a prior commitment to provide immunisations for Travellers and I expected an increased uptake in the practice-recruited children, at least for those vaccines that Travellers found acceptable. But given the numbers in the practice and QEH subgroups, I would only had the power to detect a 30% difference in uptake rate between the practices and the accident and emergency department.

Since the revised general practice contract imposed in 1990, the issue of low immunisation rates among Travellers has taken on a new significance. The immunisation targets linked to remuneration in the contract are a disincentive to general practitioners to register Traveller families (Guardian 1990). Already before the contract, my survey of East London general practitioners showed that some general practitioners would not register Travellers, sometimes not even seeing them as temporary residents. Our interviews with Travellers confirmed this state of affairs. Those general practitioners who have registered them in the past may find it difficult to achieve their 90% targets even if they are providing otherwise high quality health care to their Traveller patients. A practice in Sheffield with a strong commitment to Traveller health care calculated that - despite strenuous efforts to immunise their Traveller patients - if Traveller patients children were included in their targets, their completion rate for the triple antigen and polio would drop from 95% to 75% (Cameron 1990).

To overcome this problem the Sheffield Family Health Service Authority has offered to compensate general practitioners for any financial loss from registered Traveller children with incomplete immunisations. Other authorities have not yet taken this step. If Travellers are seen as temporary residents there is currently no financial incentive for general practitioners to provide opportunistic immunisations nor, if immunisations are given, to record them centrally. As a result of my study the East London Family Health Service Authority introduced an item-of-service payment for

the immunisation of mobile Travellers who are not registered with practices (City and East London FHSA GP News, 17 October 1991).

Partly as a result of the immunisation data and other information from my study, the child health purchasing advisory group in City and East London has specified the continuation of the Travellers' health visitor post and negotiations are proceeding for administrative and health education support as the basis of an "outreach" programme for immunisation and other aspects of preventive child health care on temporary caravan sites. With public health colleagues I am investigating the linking of different district and regional databases to provide better immunisation data for Travellers.

Travellers themselves will prioritise immunisations in response to a crisis. A case of paralytic poliomyelitis in a Traveller's child in Hackney in 1982 led to 339 Travellers being immunised on caravan sites, 82% of the Travellers known to be in the area (Lawrie 1983). The challenge for primary care is obtain this order of response on a routine basis.

5.3.5 Migrants and infectious disease

Although the problem of low immunisation rates of Traveller children must be addressed, there is another part of the discourse about preventable infectious diseases which needs to be acknowledged by health professionals who intend to intervene in this area. Historically there is a tendency on the part of the majority community to blame outbreaks of infectious disease, particularly polio, on recent immigrants or migrants. Historically this has influenced the focus of epidemiological research and health care (Rogers 1989). Even an experienced and compassionate WHO doctor like Haraldson uses a stigmatising language:

> Nomads may also carry disease to a neighbouring country across the frontier, where the disease may have been eradicated. Thus pure self-defence and instinct for self-preservation has become a major force in the engagement with nomadic people...travelling human vectors (1979:616).

Fear of contagion from Travellers is still present in our society. In one of the interviews a Traveller woman reported that when a child fell ill with polio on a site,

the local police came, evicted the families and "locked the gate". A Traveller on the Thistlebrook site in Southeast London reported that when she was travelling a group of settled people "thought we all had polio...they used to come down at night with petrol bombs and air guns" (Cannon and the Travellers of Thistlebrook 1989:62).

The problem of infectious disease has meanings other than the purely medical for Travellers and the settled community. This emotional backcloth may influence the way Travellers respond to research and health care intervention and is an aspect of their ethnic identity.

5.4. Adult health

5.4.1 Coronary artery disease risk factors

Anecdotal reports of increased cardiovascular disease among Travellers in the United Kingdom (Crout 1987, Wilson 1987), the clinic-based study of coronary artery disease risk factors in American Gypsies (Thomas 1989) and the increased SMR for cardiovascular disease for Irish Travellers (Barry and others 1989) prompted me to collect information on coronary artery disease risk factors in this study. As many Travellers are seen as temporary residents this information is not routinely collected either in East London or other parts of the United Kingdom. Even if cardiovascular risk factors were recorded in the notes of Traveller patients, these could not be analysed without a system of ethnic monitoring. The vastly increased SMR for respiratory diseases in Irish Travellers was an additional reason for the assessment of smoking rates among adult Travellers.

Smoking

As highlighted in *The Health of the Nation* (Department of Health 1991), smoking is the largest single preventable cause of mortality and a particularly important risk factor to detect in general practice where intervention may help patients to stop smoking (Jamrozik and others 1984, Richmond and others 1986). More recent evidence on the effect of passive smoking on non-smoking spouses and children

further elevates smoking as a primary target for health education (Wald and others 1992). The proportion of Travellers in my sample saying they smoked (68% men 62% women) was higher than any social group in the 1988 household survey (Foster and others 1988).

How accurate are smoking histories taken by general practitioners? In a study by Jamrozik and others (1984) of anti-smoking interventions in general practice, 23% of smokers who said they had stopped still had significant urinary cotinine levels. On the assumption that my results are also an under-reporting of smoking status, it is interesting that the rates I reported in control patients correspond to the results of the general household survey for social class. If the accuracy of reporting was the same one would expect lower rates because of the younger age structure of my sample. It is likely that smoking rates in Hackney are higher than other areas, even once social class is taken into account. There is evidence from small community surveys in Hackney that about half the adult population smokes, with roughly equal proportions of men and women (City and Hackney Health Authority 1990).

Although I did not have the resources to validate the smoking histories with urinary or blood cotinine, the inclusion of a control group makes the results for Travellers more robust. I am unable to exclude a systematic bias if Travellers and controls reported smoking differently to general practitioners. As it seems unlikely that Travellers would under-report their smoking *less* than control patients, the difference between the two groups is probably real. Travellers in Hackney have one of the highest smoking rates of any group studied in the UK.

High smoking rates are not a feature of all ethnic minorities. Surveys of South Asian and Caribbean communities in the UK suggest that they have a lower proportion of smokers than the majority population (OPCS data quoted in Gillam and others 1989). A survey of women in 1985 showed smoking rates of 5% for women of Asian origin, 22% for women of Afro-Caribbean origin and 36% for white women (Blackburn and Graham 1993).

When asked about the "main illnesses" which Traveller adults get (Question 4.4.4a) 13/26 interviewees mentioned illnesses for which smoking is an important cause: respiratory illnesses and cancer (only one Traveller we interviewed spontaneously mentioned heart disease as a "main illness"), but only two spontaneously mentioned smoking when asked about aetiological factors (4.4.4b). Later in the interview, when asked directly about the effect of smoking on health (F.1) 22/24 respondents specified one or more respiratory illnesses, six specified cancer and four specified heart disease. Knowledge about the respiratory, if not the cardiovascular effects, of smoking is widespread in this sample, but smoking does *not* figure largely in Travellers' general view of illness causation.

"Habit" or "addiction" (12/24) and calming "nerves" (8/24) were the main reason given for why people smoke (F.3), which are similar to Fields' (1987) findings in a small survey of predominantly working class smokers attending his surgery in Bristol. "Boredom" is only mentioned by one Traveller, whereas 10/25 in Field's sample mention this as a reason for smoking. In a question about the effects of maternal behaviour on fetal health (G.10), 9/15 women mentioned smoking, although only 4/15 were aware of smoking as a cause of low birth weight babies.

The question about how people can be helped to stop smoking (4.4.9d) produced mostly individualistic ("up to themselves") or fatalistic ("Nothing") answers, although two interviewees mentioned the role of "medication" and four suggested banning sales or the manufacture of cigarettes.

The Oxford healthy life survey, in which 6576 people returned a postal questionnaire on, among other issues, determinants of health, 67% of social class V and 88% of social class I respondents rated smoking as having a very important effect on health (Coulter 1987). The questionnaire listed factors, including smoking, which respondents were asked to rate in terms of importance to health. My questions are not comparable, because they address the causes of illness and did not give interviewees a range of possible answers. Nevertheless it is striking that in Coulter's study smoking was consistently given the highest rating by all social groups, above all other

lifestyle, psychosocial and socio-environmental factors, whereas in my sample environmental factors were frequently mentioned as a cause of illness and smoking was rarely mentioned until the interviewer asked directly about its effect on health.

Knowledge about the individual health effects of smoking is not the main determinant of the decision to smoke, as Graham showed in her study of mothers with pre-school children. Most were fully aware of the 'facts' about smoking but found that

> ...smoking provided a way of structuring and managing daily life: the majority of smokers noted that they smoked in response to particular situations and the majority felt that smoking helped them cope with their day to day responsibilities (1985:50).

Graham's further research among working class mothers highlighted an association between smoking and negative feelings about neighbourhood (Blackburn & Graham 1993). Specifically, a lower proportion of smokers than non-smokers felt "a sense of belonging in their neighbourhood" and that it was a "friendly place to live in." Travellers' experience of a hostile social environment combined with factors like caring for children in difficult circumstances, large families and low incomes helps to account for their high smoking rate. A review of studies on smoking behaviour found that tobacco use was still prominent among certain socio-economic groups and that many of these groups experience powerlessness relative to the rest of society (Robbins and Kline 1992). The lack of control most Travellers in Hackney experience from repeated caravan site evictions, systematic exclusion from public houses and racist attacks is an extreme form of powerlessness.

In summary, the proportion of Travellers who smoke, even in a relatively young sample, is higher than any socio-economic group in the general population and an age-sex matched sample from the same general practices. Knowledge of smoking-related illnesses is patchy, confined largely to respiratory conditions and most of the interviewed sample do not consider smoking a major cause of illness. Although most Travellers in my sample (smokers and non-smokers) were pessimistic about smokers being "helped" to stop, their willingness to discuss smoking as a problem is a pre-

requisite for intervention by health professionals. The absence of smoking cessation advice from the Traveller health visitor's log and the sporadic contact of most Traveller adults with general practitioners suggests that this intervention is not taking place.

Blood pressure

Participating general practitioners did not avoid digit preference in the measurement of blood pressure despite a training session and written instructions requesting they record blood pressure to the nearest 2mm mercury. This was not surprising, as my study took place over a relatively long period of time and was embedded in normal general practice, not specific research sessions. Use of a random zero sphygnamometer would have been unacceptable to participating doctors and costly. Moreover, even these machines do not totally prevent digit preference (Silman 1985). Since digit preference operated equally in both samples, it does not introduce bias into a comparison of Traveller and control blood pressures, although it reduced the capacity of the study to discriminate differences in mean pressures between the two groups. As a method of diagnosing hypertension, measurement of blood pressire on one occasion is not sufficient (WHO/ISH 1993), but comparison of mean pressures between two groups is still possible.

From the numbers in my study I could detect a 5-6 mm difference in mean diastolic and 7 mm difference in mean systolic. This is less helpful than it appears when one considers the age profile of my sample (mean ages 30.2 and 31.7, median ages 27 and 26 Traveller and controls respectively). Mean blood pressures of young adults from communities which ultimately have a high mean blood pressure are not raised. For example, consider mean systolic pressures in two communities stratified by age (quoted in Law and others 1991):

Table 5.1 Mean systolic blood pressure change with age

	Mean Systolic pressure	
Age (years)	Solomon Islanders	United States Whites
<20	115	113
20-29	115	123
30-39	116	126
40-49	114	132
50-59	115	139
60-69	116	147

Although the total United States sample has a higher mean pressure, this is not apparent in younger subgroups.

In my study the mean systolic and diastolic pressures were not significantly different in the Traveller and control samples or in the older (>29 years) subgroup. Using Thomas and coworkers (1987) definition of hypertension (>90mmHg), my study shows no significant difference in the proportion of hypertensives in the whole sample or the older subgroup. For the whole sample the 95% confidence interval for the difference in proportion of hypertensives stretches from -4.4 to 11.5%. Therefore there was no "epidemic" of hypertension in this sample of Travellers analogous to that uncovered in Boston, Massachussetts, the only other study of blood pressure in Traveller-Gypsies. My results also showed that it is unlikely that Travellers in Hackney had a lower risk of hypertension than the settled population.

Other than the Boston study, which deals with a different Traveller-Gypsy population and type of sample from mine, is there any other reason to suspect an increased rate of hypertension among Travellers? The increased SMR for cardiovascular disease (185) may be related to hypertension, as well as other cardiovascular risk factors (Barry and others 1989). In terms of the aetiology of hypertension, I have not confirmed anecdotal reports of high rates of alcohol consumption among Travellers and have not investigated obesity in Travellers. The repeated eviction of many Travellers in Hackney and other parts of the United Kingdom and their harassment by settled people might be considered a possible contribution to hypertension, except

that the link between psychosocial factors and hypertension is still controversial (Greenberg 1988).

This is the first study of blood pressure in Travellers in the U.K. It gives no grounds to extend the research to a community-based survey of hypertension among Travellers. Should Travellers' health visitors routinely screen the blood pressure of adults on caravan sites? While I have not demonstrated increased risk of hypertension in my study population, other parts of my study suggest that Travellers have poor access to primary care services and that men - who benefit more from treatment of mild hypertension than women (MRC Working Party 1988) - attend infrequently. When they do attend general practicies it is often as temporary residents without appointments, which makes it less likely that they will have their blood pressure checked. Therefore there might be a role for the Travellers' health visitor to check blood pressure in adults over 30 years who have not had it checked in the past five years. Of course, if a raised blood pressure is detected and confirmed over several weeks, the decision whether or not to initiate treatment in a mobile Traveller is not straight forward. Who will monitor therapy and renew the prescription? A hand-held medical record card may help prompt doctors who the patient sees in the future but does not solve the problem of access.

Random Serum Cholesterol

Serum cholesterol concentrations are an important predictor of death from coronary heart disease in men (Shipley and others 1991) and, to a lesser extent, in women (Khaw and Rose 1989). Mean cholesterol concentrations in Britain for both men and women are high, 5.9 and 5.8 mmol/l respectively (Mann and others 1988), compared to non-Western societies (Chen and others 1991). Serum concentration of total cholesterol is the most important single blood lipid risk factor for ischaemic heart disease in men (Pocock and others 1989), but in the UK there is a wide consensus (King's Fund 1989) that unselective screening of individuals at the level of primary care is not justified.

Some epidemiologists (Shaper 1991) argue against cholesterol measurements even in

individuals at higher risk of heart disease, such as hypertensives and diabetics. The value of cholesterol-lowering intervention on an individual basis is challenged on the grounds that it has no effect on overall mortality (Muldoon and others 1990) and on the grounds of cost-effectiveness (Kristiansen and others 1991). Recently concern has also been raised about possible detrimental effects of treating moderate hypercholesterolaemia (Oliver 1991) and there have been calls for a moratorium on the use of cholesterol-lowering drugs (Davey Smith and Pekkanen 1992).

My justification for measuring the random total cholesterol concentration in this sample of Travellers is independent of the debate on individual screening and treatment. Until my study there was no data from the United Kingdom or Europe about cholesterol levels in the Traveller population. Moreover, detection of a mean total cholesterol of 6.57 mmol/l in a clinic sample of American Gypsies (Thomas and others 1987) and the increased SMR for cardiovascular disease among Irish Travellers (Barry and others 1989) prompted my concern that Travellers in Hackney might have raised serum cholesterol compared to the settled population, contributing to their risk of coronary artery disease. Such evidence would have led to a recommendation to prioritise a community-based dietary strategy for Travellers rather than screening of all Traveller patients.

The skewed distribution of serum cholesterol values required logarithmic transformation of the values in order to compare the means; I found no significant difference between the two groups. The sample size allowed me to reliably detect an 0.66 mmol/l difference in mean serum total cholesterol between the Traveller and the control sample, which was less then the actual difference between Travellers and controls, 5.12 and 5.33 mmol/l respectively. Taking into account the age structure of my sample these levels were consistent with the large study of mean cholesterol concentrations in the UK (Mann and others 1988). Th lack of difference between mean cholesterol for Travellers and controls persisted in a subsample of patients over 30 years of age. Using a serum concentration of 5.7 mmol/l or greater as a definition of hypercholesterolaemia, Thomas and others (1987) found that 26/39 (67%) of their

sample were hypercholesterolaemic, compared to 20/67 (30%) of my Traveller sample.

The relationship between rising serum cholesterol concentration and increasing prevalence of coronary artery disease is continuous with no evidence of any threshold below which total cholesterol does not effect coronary mortality (Chen 1991). Although I have not demonstrated an increased coronary risk among Travellers secondary to a higher mean cholesterol than the settled population, cardiovascular disease is still the largest cause of death in Hackney and has prompted a general population strategy to lower the mean cholesterol through dietary means (City and Hackney Health Authority 1990).

In the interviews, although only 2/26 Travellers spontaneously mentioned a poor diet as a cause of illness, 15/24 said that food had an effect on their health when this was asked as a closed question. Although I did not explore knowledge about "healthy eating" in any detail, at least a third of Travellers seemed well aware of the thrust of national guidelines: decrease in saturated fats and increase in fibre and fresh fruits and vegetables. A "population" strategy to lower cholesterol levels in Travellers would need to build on this knowledge. Unlike the settled community, which has easier access to primary care and school, some of this work will need to take place on caravan sites perhaps in small group discussion with the Travellers' health visitor. My study suggests that this type of intervention should not have a higher priority than in the settled population, although information about healthy eating could form part of the general health education advice given by Travellers' health visitors. As with the blood pressure results, I could exclude a difference between Travellers and the settled population of the magnitude detected in Boston (Thomas and others 1987). With regard to further research on Travellers' cardiovascular risk, my findings imply that community surveys of cholesterol levels are not justified.

Diabetes

I included random serum glucose in the screen of Travellers because of the high rate of diabetes in the American Gypsy clinic sample (Thomas and others 1987) and because of its variable prevalence in different ethnic groups (Cruickshank 1989). The higher rate of diabetes (and hyperinsulinaemia) in the South Asian community in the UK partly accounts for their higher prevalence of coronary artery disease.

The mean age of the Gypsy sample in Thomas' study was 39 years, which was substantially higher than in my sample (30 years). This makes a direct comparison invalid, as the prevalence of Type II diabetes increases markedly over the age of 45 years in European populations. Analysis of raw data from the Boston clinic study by age showed that, in the 25 patients aged less than 45 years, the prevalence was 25%, still much higher than the level I detected: three percent. The confidence interval for the difference between the two studies was seven to 30%).

Random glucose estimations at best give a crude estimate of the frequency of diabetes in a population (WHO study group 1985). Fasting levels as used by Thomas and his coworkers may also be misleading because of problems in ensuring true fasting. Most epidemiological studies now use the short oral glucose tolerance test (two-hour value after 75g glucose load). After discussion with participating doctors and Travellers, I concluded that this procedure was unrealistic in my study, hence the reliance on the random plasma levels from venous blood.

A diagnostic level of 11.1 mmol/l may underestimate the true prevalence of diabetes, since a proportion of patients with random plasma levels between 5.5 and 11 mmols may have diabetes which would only be detected by a glucose tolerance test. This may partly account for the large difference between my results and Thomas' team. By using fasting samples they would have been able to detect more true diabetics but they may also have included patients who had not genuinely fasted, potentially increasing false positives. There are no other studies of Travellers with which to compare my result, which is not significantly different from the control sample. Despite methodological caveats, the sample size allows me to exclude prevalence of

diabetes on the scale detected by Thomas and his coworkers.

The absence of a large increase in the prevalence of diabetes among Travellers attending two general practices in Hackney is reassuring, but leaves the problem of appropriate medical care for those Travellers who are diabetic. People with diabetes require monitoring and annual screening for end-organ damage (Tattersall and Gale 1990). Mobile Travellers are at increased risk if they do not have access to a primary care or hospital diabetic clinic. The two Travellers who were found to have diabetes in the study invariably waited until they returned to Hackney to attend the diabetic clinic or an ordinary surgery in one of the practices in the study. Both Travellers had a medical record card with the details of their treatment and diagnosis and were encouraged to attend local doctors when they were in Dublin, Birmingham and Sheffield. One of these Travellers had only attended the diabetic clinic for review once in the past three years, although her adolescent children came regularly with a request for more insulin. She last lived in Hackney in 1988.

5.4.2 Alcohol consumption

The medical, psychological and social consequences of alcohol abuse are well established (Royal College of Physicians 1987, Royal College of Psychiatrists 1986, Royal College of General Practitioners 1986). The objective assessment of alcohol consumption is difficult but self-reported consumption in the context of general practice may correlate with more exhaustive assessment. Wallace and Haines (1985) showed that the results of a detailed health survey questionnaire correlated with a detailed previous week's drinking history in male but not in women patients. Laboratory tests are less sensitive than questionnaires or interviews (Bernadt and others 1982).

No previous study of Travellers had assessed alcohol consumption. Part of the stereotype of Travellers, reflected in Irish government reports, is their predilection for excessive bouts of drinking:

> Boisterous gatherings with excessive consumption of alcoholic drinks constitute one of the few pastimes [sic] available to them...many of these gatherings end in conflict. (1963 Report of the Commission on Itinerancy; quoted in Adams 1973:184)

In the epidemiological part of my study, general practitioners asked Traveller and control patients to quantify how much alcohol they had drunk in the past week. Although this question may not accurately reflect true consumption, using the same question for Travellers and controls allowed comparison between the two groups. The comparison would only be invalid if there was a systematic difference in accuracy of reporting between the two groups. I cannot exclude this possibility.

In women, the proportion reporting more than 14 units or 28 units per week was small and not significantly different in Travellers and controls (Table 4.35). In men, 43% of Traveller and 19% of controls reported drinking more than 21 units/weeks which is not a significant difference. The small sample size limits the power of this comparison; to reliably detect a real difference of this magnitude I would have needed a total sample of 130 men. Six Traveller and no control men reported drinking more than 42 units/week which is not significantly different. These results of Travellers' self-reported alcohol consumption in comparison with the reports of age-sex matched controls do not support the hypothesis that Travellers in Hackney have a disproportionate problem with alcohol abuse. This conclusion is more robust with the sample of women, although I would have been unable to reliably detect differences of less than 25% in the proportion of women drinking above the 14 or 28 unit limit. With the small sample of men the analysis is highly prone to a Type II error and it would not be safe to conclude that men in this local population of Travellers have the same pattern of alcohol consumption as the settled population.

In the interviews with Travellers it was clear that alcohol abuse was a matter of concern. As with most of the other issues discussed in the interviews, there were a range of opinions, but descriptions of the damage that alcohol can cause to health were vivid and often referred to family members. Not all interviewees were able to specify the negative consequences of alcohol consumption, but nobody suggested that there were none. Generally the range of problems highlighted in the interviews reflect

those recognised by medical and social research. The social consequences of alcohol abuse were given as much if not more weight than the medical effects despite the interview question being pitched towards "health" effects.

Half the interviewees rejected the idea, embodied in one of my questions, that alcohol had any positive health effects. This included people who felt "moderate" drinking was acceptable, as well as the quarter of the whole sample who said they were teetotallers. Those who felt it could have a positive health effect gave a wide range of answers, from the assumed iron content of Guiness to the advantage of mild dis-inhibition socially. Only a third of women spontaneously mentioned alcohol consumption adversely affecting their baby during pregnancy and several mentioned Guiness consumption while pregnant as a positive activity.

In the design of the questionnaire I missed the opportunity to ask Travellers about their knowledge of "safe" levels of alcohol consumption. Discussion of these levels is a useful starting point for targeted health education (Hartz and others 1990). The interviews also did not explore Travellers' views about how people with alcohol problems could be helped and whether there was a role for health professionals. But the level of concern about alcohol implies that health education around this issue would probably be welcomed.

5.4.3 Cervical screening

Effectively managed cytological screening for preinvasive cervical neoplasia reduces the incidence of cervical cancer and related mortality. Three yearly screening can reduce the incidence of invasive disease by over 90% (IARC Working Group 1986), although simulation studies suggest that the "greatest reduction will be achieved by the most complete coverage of the population" (Smith and others 1989:1662), even with a longer screening interval.

Cervical screening is a central part of general practitioners' preventive work and is the focus (since 1989) of specific performance targets: 50% or 80% of women aged

between 18 and 64 need to have had a cervical smear in the past five years for specific payments to be made to the practice by the Family Health Service Authority. Effective population screening requires a call and recall system with accurate information about the last smear and address of eligible women. In 1985 the Department of Health and Social Security recommended that each district health authority establish such a system based on the age-sex registers of family practitioner committees. The implementation of this system is difficult in inner city areas where the populations are very mobile and the family practitioner data base is inaccurate. A study (Beardow and others 1989) in an inner London district showed that 69% of letters sent to women by the family practitioner committee were either unnecessary or sent to the wrong address. Baker and Klein (1991) showed that deprivation and population mobility were important independent factors accounting for the variation in uptake of cervical cytology between family health service authorities: the higher the Jarman index and list inflation, the lower the cervical smear rate.

Different groups within the population have different cervical smear rates, with older women and single women consistently less likely to have had smears. Most studies also show a steep class gradient in the uptake of cervical smear screening, with women from higher social classes having higher smear rates than women in lower social classes, although this is not a universal finding (Editorial Committee of the Cardiff Cervical Cytology Study 1980). Some ethnic minority groups also have lower cervical smear rates than the majority population. In a study of 337 randomly selected Asian women in Leicester, McAvoy and Raza (1988) found that only 35% of eligible women had ever had a cervical smear. Several studies have investigated women's reasons for not having a cervical smear. For example, Charny and coworkers (1987) in a questionnaire-based community survey of 517 Welsh women who have never had a smear found that half the sample either did not know where to get a smear or had never been invited to have one. Only a quarter of the sample had chosen not to have a smear because of embarrassment, fear or a view that it was "not worth it". Meadows (1987) in semi-structured interviews with 107 women who were overdue for a smear found only a quarter with a "major objection" to the procedure, with half of the sample not objecting but not ascribing any importance to cervical smears.

At the time that I was designing my study there was no information about cervical smear rates among Traveller women. Since then, MacAuley (1991) has reported an audit of notes of 77 Traveller women aged between 25 and 65 in his Belfast practice: only 11 had any record of a cervical smear. When he visited the caravan site, 57 of these women had left. Of the 10 he was able to interview, nine had a smear done in the past 18 months. It is difficult to draw any conclusions from these observations. Because of Traveller mobility, uncertain access to primary care and possibly a culturally specific negative perception of smears, I hypothesised that the rate among Traveller women in Hackney would be lower than the settled population. By choosing to study a sample of women presenting for primary care, I am determining a maximum smear uptake rate for Travellers in Hackney, since it is probable that Traveller women who have never had a cervical smear were less likely to have seen a general practitioner during the study period.

Thirty-six percent of my sample of eligible women said that they had never had a cervical smear. Of these 22 women, all but two had at least one baby in the past ten years and had received some antenatal care. There was no age difference between those women who had and those who had not had a cervical smear. Fourteen percent of my eligible control sample had never had a smear. The 22% difference between the two samples (95% confidence interval = 7 to 37%) probably reflects a real difference in uptake between Travellers and the local settled population.

In the interviews, two of the eligible women who had not had a smear clearly did not attach any importance to the procedure and one quarter of the sample, including women with recent smears, did not feel smears were important or were not sure if they were. Another eligible women who had not had a smear said that "we" do not have smears before the first baby is born and never during a pregnancy. When asked who "we" was, she said she meant Traveller women as a whole. My impression from offering Traveller women cervical smears in antenatal clinics is that this is a general view. This may partly account for the number of women who have never had smears after several pregnancies, particularly as evictions may result in Travellers missing post-natal checks (Durward 1990). When asked about their most recent pregnancy,

less than half the interviewed women had a six week post-natal check. The problem of smears during pregnancy needs to be further discussed with Traveller women to clarify the meaning of their refusal to accept smears until after delivery.

Discussions about cervical smears would also be an opportunity to augment knowledge about their usefulness. All but one of the women interviewed about smears said they knew what they were, in so far as they were aware that they involved an internal examination and use of a speculum, but less than half knew that the procedure had any connection to cancer. Only two women specified the prevention of cancer as the goal of cervical screening. Other than reluctance to have a cervical smear during pregnancy and ascription of a low priority to cervical smears among some of the women, the gender of the doctor may also deter Travellers from getting smears. Traditional Traveller culture is strongly dichotomised between men and women, with a strong emphasis on female modesty, in contradistinction to the "gypsy" stereotype held by settled people. Okely writes that

> ....since, in external relations, Gypsy women are always vulnerable to sexual contamination by the Gorgio, they must be taught that their ever-present sexuality and fertility are dangerous. The women's dress, deportment and behaviour are matters for constant public scrutiny. They must shield their sexual parts, control their movements... (1983:211)

This modesty in Traveller culture may partly explain why three quarters of the women we interviewed said they would be more likely to have a cervical smear if it were performed by a woman. Women from some ethnic groups, such as South Asian Muslims, object to gynaecological examinations from male doctors (Fuller and Toon 1988), but a preference for a female health worker to carry out cervical screening is not exclusive to ethnic minorities. In a postal survey of 420 women in Hampshire, Nichols (1987) found that almost 60% had that preference, with a higher proportion among older or working class women. This result is not strictly comparable to mine since Nichols asked about *preference* for a women practitioner, rather than the likelihood of accepting the procedure and because a postal survey is a different context from a face-to-face interview.

As with childhood immunisation I hypothesised that bringing the cervical screening service to caravan sites would be viewed favourably by Travellers. This was not the case, with over two thirds of women strongly opposed to this on grounds of embarrassment and lack of privacy on the site. This reluctance for cervical smears on a site is consistent with a perception of internal examinations as a polluting activity, which transgresses the boundary between the inner and outer body that is central to Traveller-Gypsy identity. Okely explains the near-universal preference for hospital birth by Travellers along similar lines:

> Rather than being a safety measure for the women, hospitalisation is a convenient way of dealing with the polluting act. The Gorgios are given the task of supervising the process and disposing of polluted articles (1983:210).

I do not have any direct evidence that the problem with cervical smears on a site relates to this symbolic issue, which would in any case not be stated explicitly but emerge from a detailed analysis of Traveller discourse. On a more prosaic level, women entering a health caravan on a site might feel that everyone on the site, including men, would know that they were going to have a gynaecological examination. The potential embarrassment in this situation would not be particular to Travellers. In any case, the interviews suggest that provision of cervical screening on caravan sites is unlikely to be an effective method of increasing the smear rates of Traveller women. Increasing the availability of female general practitioners or nurses capable of taking cervical smears might increase cervical smear uptake by Travellers, but would have a greater impact if coupled with health education about cervical cytology. Targeted health education via videos has proved effective in raising cervical cytology uptake among women of Asian origin (McAvoy and Raza 1990), but the preferred method of our respondents was one-to-one or group discussion on caravan sites. A greater receptivity to cervical smears by Travelling women would not resolve the problem of recalling mobile Traveller women who are due a smear and either are not registered with a general practitioner or are living elsewhere at the time of recall. Reminding Travellers about cervical cytology during primary care consultations and visits to temporary caravan sites will be necessary.

5.4.4 Views on the origin and prevention of illness

Lay ideas about illness are seldom formalised and usually expressed in the form of specific stories about family members (or friends), only becoming explicit when decisions have to be taken about actual illness episodes.

> People may be quite uncomfortable about expressing and arguing ideas which normally remain tacit background resources to be drawn upon when coping with their own or other people's illnesses (Fitzpatrick 1984).

Blaxter (1983) and Cornwall (1984a) used a relatively unstructured "ethnomedical" method in their investigations of lay aetiological models among 46 working class women in Glasgow and several working class families in East London respectively. Their data do not consist of answers to predetermined questions, but general conversations around issues of health and illness which were tape recorded and submitted to a verbal and content analysis. Pill and Stott (1982, 1985) in a sample of 204 Welsh mothers used a semi-structured questionnaire with a combination of structured pre-coded questions and more open-ended questions about attitudes to health, concepts of causation and responsibility. The answers to the latter part of the questionnaire were recorded and coding reliability was ensured by a regular review panel. At the other end of the methodological spectrum are large pre-coded postal questionnaire surveys like Coulter's (1987) with 5754 responses from a stratified random sample of Oxford residents exploring social class variations in beliefs about health determinants.

In the context of primary care Risdale (1988) maintains that research around lay health beliefs provides a broader frame of reference for general practitioners within which they can articulate individual patients' views as part of the consultation. In the absence of previous research about Traveller health beliefs a fully structured questionnaire would have been inappropriate. I could have persisted with tape-recorded unstructured conversations which are appropriate "in the pilot phase of a study which is opening up a new field of research (Risdale 1988:90)"; but I would have lost the opportunity to systematically explore issues highlighted in the other parts of the study. Therefore interviews were based on a semi-structured questionnaire and in the area of general health beliefs I restricted the discussion to six questions (4.4.4.)

eliciting Travellers' views on the "main" illnesses they and their children get, their causes and how they might be prevented. With adult illnesses the question about prevention was deliberately couched to elicit answers about personal behaviour. The only hypothesis I tested in the health belief section of the questionnaire interviews was that it is possible to explore aspects of Traveller beliefs through semi-structured interviews. Understanding of these beliefs might help health professionals address Travellers' priorities and design appropriate health education initiatives (Mares and others 1985).

For adults, respiratory illnesses were most commonly mentioned by respondents. Heart disease was only mentioned by one respondent and cancer by fewer than a quarter of respondents. This is probably because the term "main" in the question was interpreted as "common". I might have had different answers if the questions had referred to life-threatening illness. In children the most frequently mentioned conditions were diarrhoea and vomiting, followed by respiratory illnesses. The question about illnesses made some Travellers uneasy. This was partly because listing diseases is not the way lay people - Travellers or the settled community - usually talk about illness. Furthermore, without exploration of what Travellers mean by the illness terms they used, I cannot assume a direct correspondence with medical discourse (Good 1977). Some respondents were also concerned that the question implied that Travellers in some way had different, more serious illnesses than other people which could be used to stigmatise them, as in the case of polio. This was not a successful question and, if one aims to understand Travellers' views of illness, no substitute for qualitative analysis of discussions around the illnesses of families and friends.

This criticism also partly applies to the questions about aetiology and prevention, although answers to these questions gave an important insight into Travellers' views. One quarter of Travellers did not give any causes of illness, neither external nor lifestyle factors. Most of the respondents stressed caravan site conditions as a major etiological factor both in adult and childhood illness. Although the question on adult prevention (4.4.4b) was slanted towards personal lifestyle choices, half the respondents talked about caravan site provision and safety. The interviews clearly

revealed the dilemma of many Travellers between living on inadequate sites and abandoning their way of life. More than one third were fatalistic about any prevention for adults, whether this was environmental or personal, and one quarter felt similarly about childhood illnesses. Smoking was only mentioned spontaneously by one tenth of respondents and other "lifestyle" measures were only mentioned spontaneously by two respondents.

This emphasis on external factors is not unique to Travellers. The discrepancy between doctors' and patients' views of illness causation was demonstrated in the context of general practice by Martin and others (1991) in a questionnaire study of 500 consultations. They showed that patients perceived their problems as caused by external factors such as "infection, trauma, stress and social problems, physical and environmental factors and pregnancy" whereas doctors characterised the causes of the same presenting complaints as secondary to "lifestyle factors that affect health such as obesity, alcohol and smoking."

Although my method only scratched the surface of my respondents' beliefs about illness aetiology and prevention, the interviews suggested that lifestyle issues were not particularly important, whereas environmental concerns and a need to have control over their mobility were paramount. The overwhelming emphasis on environmental conditions reflects the poor site conditions experienced by most of the Travellers we interviewed. None of the Travellers who lived on Hackney sites had running water. They relied on local factories or garages which sometimes required payment. Illegal temporary sites rarely had rubbish collections and no toilets. It is likely that Travellers' living conditions in Hackney and views of disease aetiology are an example of Coulter's generalisation from her questionnaire study:

> The greater emphasis that working class respondents ...placed on the effect of socioeconomic and environmental factors on health probably reflects social class differences in the experience of adverse social conditions (1987:535).

On the other hand, surveys of the settled population's views on disease aetiology do not consistently show a concern with structural factors or a correlation between low socio-economic status and a recognition of "external" aetiological factors. Blaxter's

(1990) health and lifestyle survey of 9000 people found that questions about the causes of specific diseases and ill health in general elicited behaviourial replies. Moreover, structural or economic factors were mentioned *more* commonly by professional and managerial respondents. More recent work by Blaxter (1993), returning to qualitative analysis of longer interviews with middle-aged women in social classes IV and V, confirms the emphasis on lifestyle factors and personal responsibility, but in a more complex form, combining "external" and "internal" explanations.

In this light it is striking how few Travellers mentioned individual behaviour in the context of prevention. Although I did not use Pill and Stott's (1985) five questions to ascribe a "Salience of Lifestyle Index" to my respondents, it is clear that as a group they would have had a very low score. This has implications for health education not only with Travellers but other groups which do not consider personal lifestyle factors particularly important.

> Indeed a recent trend in health education which concentrates on presenting the 'facts' about individual behaviour and attribute irresponsibility to those who do not comply may be counterproductive in the long run because this approach is seen to ignore the...social and environmental factors currently recognised by the target population (Pill and Stott 1985:989).

It is possible that Travellers emphasise environmental (and mobility) factors more intensely than other groups. But to test hypotheses about the cultural specificity of Travellers' general health beliefs would require a larger sample and a settled control group or the use of a validated questionnaires from other studies of health beliefs. It is premature to differentiate Travellers' beliefs about disease causation and prevention from that of other groups and the settled population as a whole. Travellers' views, like those of other people are balanced

> ...between the pursuit of an almost universally valued goal (good health) and the realistic recognition that some barriers exist on the road which may not be surmountable through personal individual effort (Davison and others 1992:679).

Davison and his colleagues reject the conflation of "fatalism" with rejection of lifestyle solutions to specific health problems. Although "true fatalism" does emerge

from interviews with some Travellers, their demand for improved sites and control over mobility transcends the fatalism/lifestyle control dichotomy which informs much of current health education. These factors are potentially controllable but lie outside *individual* responsibility. Ironically, in our interviews, Travellers's recognition of structural factors in disease causation was more congruent with epidemiological models of disease causation than the individual lifestyle focus of most health promotion activity. If health promotion work with Travellers is to be successful, we need to acknowledge and incorporate their "lay epidemiology" which weaves together individual, environmental and fatalistic perspectives. By the same token, I found that Traveller involvement in research was enhanced when their priorities were addressed.

A specific area of prevention I addressed in more detail in the interviews was health in pregnancy. Half the women mentioned a "good diet" or "fruit" as important for keeping healthy in pregnancy. Over half the women mentioned smoking and over a third mentioned drinking as harmful to the "baby" in pregnancy. Six of the nine women who mentioned smoking actually smoked during their last pregnancy. The specific effects of smoking and alcohol in pregnancy were not widely understood by the women. A minority of Traveller women, most of whom already had several children, had little explicit knowledge about health maintenance during pregnancy, despite attending the antenatal clinic. I did not ask about antenatal classes, although local community midwives cannot recall any Traveller woman ever attending their classes.

Antenatal care was not addressed specifically in this study, because preliminary review of Travellers' antenatal notes showed relatively good attendance at clinics and this was confirmed in discussion with the Travellers' health visitor. The interview revealed that two thirds of the respondents would want to see the doctor in the first trimester, which may mean that previously documented late booking by Travellers (Linthwaite 1983) may be a function of poor access to antenatal care rather than the choice of pregnant Travellers. O'Byrne (1990) found that over a third of her sample had booked in the first trimester and over three quarters by the end of the second trimester.

5.5 Primary Health Care & Travellers

5.5.1 Primary care

Primary care settings are those where patients have access without referral by a health professional and include accident and emergency departments, community health services (family planning, child health, well women clinics) and general practices.[1] Registration with a general practitioner is a right in the United Kingdom, recently reiterated in the Patient's Charter (Department of Health 1992) although a general practitioner is under no obligation to register any patient or even to see them as a temporary resident. Access to a general practice is important because general practitioners and the primary care team can:

- manage the majority of acute and chronic illnesses;
- refer the patient for secondary or tertiary care;
- offer preventive procedures like immunisations or screening procedures like blood pressure measurement and cervical smears;
- provide opportunistic (or invited) health promotion advice.

My study demonstrates that Travellers in Hackney had problems gaining access to general practice and shows clearly that even those who saw general practitioners were not receiving the preventive care which is now considered integral to good general practice (Stott 1983, Tudor-Hart 1988). Not all under-utilisation of services is due to poor access. Marsh and Channing refer harshly to "particularly apathetic families...who stubbornly refused all [preventive health]...overtures (1988:176)." More charitably, Daniels (1982) argues that under-utilisation may reflect "principled, informed choice". Travellers choices about the pertussis vaccine and antenatal smears arguably fall into this category. I explored the reasons for poor access to preventive care primarily through interviews with Travellers, but also through a questionnaire to general practitioners and an evaluation of the work of the Travellers' health visitor.

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[1] My definition is more logical than that given by the Department of Health (1988) which excludes accident and emergency departments because they are part of hospitals.

5.5.2 Exclusion of Travellers by general practitioners

Anecdotal reports and one poorly designed study in East Anglia (Linthwaite 1983) led to my question whether Travellers were explicitly refused health care by practices in Hackney, which contributed to their diminished access to primary care. I thought evidence for this would come from Travellers themselves and did not imagine that general practitioners would admit to discriminating against Traveller patients. Nevertheless, in the questionnaire sent to all practices in East London, I asked whether they accepted Travellers as temporary residents. Ten percent of practices stated they did not, with one respondent writing that he was "not equipped to treat them." Further exploration of the reasons these general practitioners excluded Travellers would have required longer questionnaires or personal interviews.

In the interviews Travellers were asked about "not being able to see a doctor" in Hackney or elsewhere when they wanted to see one (4.4.5abc). Stated baldly this may seem an over-inclusive question, confusing refusals to see a patient on the same day for a non-urgent problem with a total refusal to provide care, but the interviewer followed up on the initial response to ensure the answer only covered the latter case. About one quarter of Travellers reported exclusion by practices in Hackney and two thirds reported exclusion in other areas. I cannot estimate the number of practices in East London which refuse to treat Travellers, as it is unlikely that all such practices would admit to this policy. Because the Travellers we interviewed are not necessarily representative of Travellers as a whole in Hackney, I cannot estimate the true proportion of Travellers who have ever been refused treatment in Hackney.

It is safe to say that the experience of discrimination by general practitioners was widespread and almost taken for granted by Travellers, who spoke about it in a resigned way. Surprisingly it did not lead to a general cynicism about doctors since three quarters of respondents felt that the doctors who did see them treated them with respect and two thirds were generally happy about the way doctors communicated with them. (4.4.5ef) On the other hand, a questionnaire can obscure more complex perceptions of doctors.

Evidence for exclusion of ethnic or other groups from general practice does not usually rise above the anecdotal, although Johnson (1986) in a demographic study of general practice registration by ethnic group thought this was one interpretation of variation in his data. One study of the access of homeless people to general practice showed that half of the subgroup who slept rough had either been refused registration or expected to be refused (Stern 1989 quoted in Shiner 1991). In a questionnaire-based survey of general practices in Waltham Forest, of the 16 practices responding, one said they refused to treat single homeless people on a temporary basis (Waltham Forest Community Health Council, unpublished report 1990). The response rate (22%) contrasts with the high response rate achieved in my questionnaire survey of similar design. Perhaps a department of general practice is perceived as a less 'hostile' source of a questionnaire by general practitioners than a community health council.

Exclusion of Travellers from some practices parallels their exclusion from other facilities, such as public houses, in East London. It contributes to their experience of discrimination and rejection by the settled community, even if they ultimately find local practices who will accept them as patients.

5.5.3 Choice of services

The interviews with Travellers revealed their uncertainty about access to general practitioners, especially when they had moved into a new area or were passing through. This uncertainty probably results in an increased use of the accident and emergency department for conditions which could be dealt with in general practice. This 'inappropriate' use of hospital services is coupled with a perception of many of the respondents, that the care provided by accident and emergency departments and general practices are interchangeable. When asked what would make them more likely to attend a hospital or surgery (4.4.5j), a wide range of answers was given. In relation to accident and emergency attendance, severity of the illness was only mentioned by one respondent and most answers referred to ease of access. This contrasts with findings of a one-month interview-based study of all children under

nine months old presenting at Queen Elizabeth Hospital (Hackney) in 1989, in which less than a quarter of parents interviewed specified ease of access or problems of access to their general practitioner (Bedford and others 1992). The only explicit reason given for attending a general practice (4.4.5k) was the presence of their medical records. This question can be criticised because it asks respondents to abstract reasons for choosing one service or another. To genuinely understand why Travellers make these choices would require a longer, less structured discussion about specific events and the choices which were made.

Travellers are not alone in using accident and emergency departments to receive primary care which could have been given in general practice. Approximately half the patients attending urban accident and emergency department present problems amenable to general practice management (Cohen 1987). Although this use may appear inappropriate to health care professionals and health care purchasers, it may be an appropriate choice from the patient's perspective. Choice of an accident and emergency department over a general practice is potentially determined by a wide range of factors including

> ...the perceived availability, accessibility, competence and convenience of general practitioner services...but patient surveys indicate that the perceived need for urgent care is probably more influential than dissatisfaction with general practice *per se* (Dale 1992:90).

Our interviews suggest that in the case of Travellers neither urgency nor general dissatisfaction with general practice is as important as the inaccessibility of general practice to many Travellers. Inaccessibility is not just a function of exclusion or high mobility, but includes problems in making and keeping appointments and conforming with surgery times. For Travellers who are either excluded by a general practice or find access difficult, accident and emergency departments have a "safety net" function, as they do for other vulnerable groups like the homeless, refugees or socially isolated individuals. Like these groups, many Travellers find it difficult to negotiate the registration formalities, surgery hours and appointment systems of general practice. Increased "primary care" use of accident and emergency departments by ethnic minorities has been documented in London (Dale and others 1991). In the

United States Andersen and others (1986) found no difference in emergency room use between Hispanic and white groups. Even if specific groups have increased use of accident and emergency departments, this does not necessarily mean decreased use of general practitioner services. In a study of 522 homeless people in bed and breakfast hotels in north west London, Victor (1992) found that both accident and emergency *and* general practitioner attendance were increased compared to the local resident population.

As with frequent use of accident and emergency departments, travelling long distances to see a general practitioner may also reflect problems of access to local practices. The distance travelled by patients recruited in the epidemiological part of my study is difficult to assess since many of the addresses given to receptionists were false. There will be a systematic bias toward the reporting of Hackney addresses, as Travellers felt this increased their chances of being seen in the practices. Therefore it is striking that 12% of the Travellers recruited in the two Hackney practices gave addresses outside Hackney and 8% outside East London. The true proportion will be higher; of the 17 Travellers interviewed in-depth at the Lower Clapton Health Centre, eight revealed that they came from Haringey and Tower Hamlets. The interviews did not include a question about why these Travellers chose a non-local general practice, although informal discussion suggested that the presence of their medical records, being "known" by the general practitioners and uncertainty about acceptance by local doctors were important factors. Travellers considered themselves "registered" at practices although they were being seen as temporary residents and resided many miles away.

5.5.4 Access to preventive services

Exclusion from some practices and the use of accident and emergency departments does not account for the low immunisation and cervical smear rates among the Travellers we studied, since two thirds of the children and all the adults were recruited in two practices which did not exclude Travellers. In the case of immunisation, rates were low even in the children recruited in practices, which implies that access to a general practitioner is no guarantee of access to preventive

services. Use of health authority child health clinics is minimal: no clinic in our survey saw more than one Traveller child per month.

In my discussion of the immunisation results I suggested that, in the case of the double antigen and polio vaccines, Travellers were not choosing to avoid the intervention, but that the problem was primarily one of access to the service and perhaps the relatively low priority which Travellers ascribe to immunisations. Moreover, the immunisation role of general practice was not recognised by the Travellers we interviewed. When asked what would make them go to a doctor (4.4.5i), only one respondent spontaneously mentioned immunisations. On the whole the Travellers we interviewed did not associate general practitioners with preventive health care. This mirrors general practitioners' perception of the health care which they provide to Travellers: acute interventions with little continuity of care or information about past medical history.

Opportunistic immunisations of siblings or non-pyrexial children is complicated by a tendency for many Travellers not to make appointments, which means the children are seen as 'extras' or in emergency surgeries, when the practitioner is least likely to provide preventive health care. From the general practitioner questionnaire survey, two thirds of practices with appointment systems said they "often" had problems with Travellers making or keeping appointments.

The majority of women interviewed had post-natal care from a midwife or Travellers' health visitor after their most recent delivery, although less than half had a six-week post-natal check. The length of the interview precluded exploration of the reasons for this low uptake of the six-week check.

5.5.5 Role of the Travellers' Health Visitor

The evaluation of the Travellers' health visitor (THV) role in Hackney was based on discussions with the current post holder, a retrospective and prospective study of her workload, interviews with Travellers and the general practice questionnaire.

The post of THV in Hackney was one of the first established in the United Kingdom to help address the unmet health care needs of Travellers (Lawrie 1983). Most health care initiatives around Travellers' health care depend on peripatetic specialist workers (Durward 1990). There is still a debate about the extent to which these workers should provide a full range of services on caravan sites, while simultaneously

> ....encouraging Travellers to make use of the regular services and...educating health workers in other areas to that they are willing to accept Travellers and treat them properly (Cornwell 1984b:21).

Low cervical smear and immunisation rates which are not explicable by Traveller refusal to have these interventions reflects a poor standard of primary care for Travellers in Hackney. This poor standard has persisted despite the presence of an experienced Travellers' health visitor. Our analysis of her work revealed limits on her capacity to address this problem, because of the large number of other issues she tackled and her vast catchment area. Discussions with the post-holder and the prospective study revealed a wide range of tasks including community development and advocacy work, health promotion and facilitating the use of primary and secondary care services. In the absence of other professional involvement the THV was often the main source of medical, welfare and social advice. Her emphasis of advocacy is consistent with the move away from traditional health visiting by other Traveller health visitors (Crout 1988).

Advocacy is a response to the marginal and relatively powerless position of Travellers vis-a-vis state institutions and addresses issues which Travellers consider important. The adoption of the advocate role in hospital nursing is a general trend within nursing in the United States and, more recently, the United Kingdom (Morrison 1991). Transferred from the hospital ward to the community, the advocate role changes because of the increased autonomy of clients compared to hospital inpatients, but it still involves mediation between a client group and potentially hostile parties. In the case of Travellers these parties can range from the police to environmental health officers to general practitioners. In the United Kingdom, Travellers' health visitors have pioneered advocacy as an intrinsic part of the nursing/health visiting role. But

time spent in this role may conflict with other more mainstream health-care activities. Immunisations were not given by the THV on caravan sites. Although she sporadically went out with community medical officers or general practitioners who did immunise children, she did not do this during the evaluation period. The decision not to provide immunisations on sites stems partly from a judgement about priorities and partly from a perception by the THV that this provision undermines integration of Travellers into primary care services. With immunisations, as with antenatal care and women's health care, the THV's goal was always to encourage Travellers to attend local general practitioners or community clinics. One consequence of this policy is a separation of her discussion of immunisation with Traveller parents from the actual procedure. Not all THV's agree with this approach. Lawrie, the previous East London post holder, wrote:

> I find it most effective to do as much work as possible on the site in the trailers. The women feel more comfortable on home ground and no time is wasted in failed appointments (1983:27).

Aside from the THV's ubiquitous role which went beyond traditional health visiting, her capacity was limited by the geographical area she covered: four health authorities in North and East London. In the two-week prospective study period almost one fifth of her time was spent travelling either to sites or to health care institutions. Her wide catchment area and the density of London's traffic reduced the amount of time available for patient care but allowed her to maintain contact with families wherever they moved within the four health authorities.

The interviews with Travellers showed that the majority either knew the Hackney or Haringey THV by name and most felt they could talk with her about a wide range of problems, not necessarily medical (4.4.5h). When asked about their preferred form of health education half the respondents mentioned "someone coming round" and most specified the THV as the best person to do this (4.4.6c). Since over half the interviews took place in the health centre where the THV was based, there was a strong sampling bias towards Travellers who knew of her existence.

The THV's liaison role with general practitioners was less well developed. Almost

half the general practitioners in Hackney and Tower Hamlets who had seen Traveller patients in the previous year had no knowledge of the THV (Table 4.5). Of the general practitioners who knew of her existence, more than one third had no contact with her (Table 4.6). Development of the THV's liaison role, not only with general practitioners and other health workers, but also environmental health officers, teachers and local authority Traveller officers, was limited by lack of time and the absence of administrative support. Time constraints resulted not only from travelling time and the wide range of tasks she performed, but the actual number of clients she saw every week: mean of 92 with a range of 24 - 240 over the three month evaluation period.

In summary, the East London THV's close relationship with Travellers did not result in a high uptake of preventive services, nor was she sufficiently well-known by general practitioners across East London to fulfil her liaison role. In the area of immunisations, integration into mainstream primary care was still a distant goal and the decision, on grounds of principle and time, not to provide immunisations on caravan sites probably contributed to the low uptake.

5.5.6 Patient-held medical records

Many discussions of Traveller health care conclude that hand-held medical record cards would be a useful innovation (Cornwell 1984b, Durward 1990). Although these cards have been introduced by a number of Traveller's health projects, starting with Sheffield (Wilson 1987), there has been no audit or evaluation of their role. It has not been clear whether Travellers approve of their use or would show them to health professionals. In an attempt to address this question for Travellers in Hackney I asked that each Traveller for whom data was collected in the epidemiological part of the study was also given a handheld record card, with a request to bring it to any consultation with a doctor or health worker and show it to the THV if she visited the site. The mobility of the majority of Travellers in Hackney precluded a longitudinal study of individual Travellers to find out if they still had the record and whether they had been used. My method involved a detachable postcard (with a "freepost" address) which signalled that the record was used once (appendix E).

The results show that almost a third of Travellers who were given cards used them at least once over the monitoring period (a minimum of 12 and a maximum of 31 months after receiving the cards). The proportion was higher in children, lower in women and lower still in men. The proportion of Travellers for whom there is evidence that the record card was used are underestimates of the true proportion when those who did not consult a health worker are excluded. I do not have a denominator for these figures since I do not know how many of the group from whom no card was received consulted a health worker during the monitoring period. In the case of children, where 69% of the total sample was under five years of age, it seems likely that most would have had some contact with an accident and emergency department, general practitioner or health visitor in the year after the index consultation. Therefore the relatively low record card use for children (37%) casts doubt on the hope that hand-held medical records will solve the problem of lack of information noted by the doctors in our questionnaire survey.

Why were the hand-held medical records not used by a higher proportion of Travellers in our study? In interviews with Travellers, half of whom said they had been given a card either for themselves or their children[1], all said they thought that carrying their medical records would be useful in some circumstances, especially if they were travelling in an area where they did not know the doctors. This was not necessarily because the record would be useful for the doctors but because it might ease Travellers' access to general practitioners. There was scepticism about healthy adults needing hand-held cards, which is probably reflected in the low usage rate I detected. Important factors highlighted by studies of handheld records which showed a high usage in the majority population were the quality of instruction to parents (Pearson 1985) and the publicity to health professionals beforehand (O'Flaherty and others 1987).

[1] I know that another quarter had also received a card but, by the time of the interview had forgotten or chose to deny it!

All of the 59 returned cards came from the three centres where patients were recruited or from the East London THV. This contradicts the statements of interviewed Travellers stating that they would find them most useful when in other areas and evidence that the cohort of Travellers to whom we gave medical record cards spent time outside of Hackney during the study period. I do not know if the absence of responses from outside Hackney was because (a) Travellers did not bring the records with them when they consulted in other areas or (b) Travellers brought but did not volunteer the records when seen by health professionals or (c) the doctor or health visitor they consulted did not send us the tear-off card. Under half the hand-held records seen by the doctor or health visitor at a subsequent consultation were considered "useful" by the health professional who returned them. Most of those which were not useful were from patients for whom the doctor held notes or had issued the hand held record in the first place.

Despite the methodological problems in tracing record card use and the small interview sample, some conclusions can be drawn from this evaluation of hand-held record cards. There is no evidence of their use outside of the centres where they were issued and, in these centres, only a minority of Travellers brought the card with them on subsequent consultations and presented it to a general practitioner or health visitor. Moreover Travellers thought that hand-held records were only useful in specific situations and were unlikely to use them in all consultations.

From these data I cannot recommend universal provision of hand-held medical records to Travellers. On the other hand, the dearth of information about the immunisation status of many Traveller children and about significant medical history in some children and adults continues to overshadow consultations with Traveller patients. Therefore even patchy use of hand-held records in children would help decisions about immunisations. In 1993 Hackney has joined other areas in the UK in providing *all* new born children with parent-held medical records (Tan, letter to all practices in City and Hackney health authority 22/3/93). By raising general practice awareness of hand-held records, it is likely that Traveller children will particularly benefit. In the case of adults, I do not think there is a case for the majority of

Travellers to be issued hand held medical records. They should be targeted for those patients with a chronic medical problem which needs monitoring, like diabetes or hypothyroidism.

In this study provision of handheld records by general practitioners and accident and emergency department nurses did not prove conspicuously successful. One specific reason for this may be that provision of the cards was combined with an ordinary consultation plus data collection and, in the case of adults, venesection. Practitioners and nurses may not have had time to fully explain the cards, reducing the likelihood of use (Pearson 1985).

5.6 Summary of findings

I concluded my review of the previous literature on Traveller health care with nine questions (p.57) which I have tried to answer in the course of this study.

Child health

1. There was no significant difference in mean birthweight or low birthweight babies between my sample of Travellers and controls from the local settled population. Travellers had a higher proportion of high birth weight babies. There was no difference in Traveller and control children's weight distribution, but only very large differences could have been detected.

2. There was a large difference between immunisation rates of Travellers and the local settled population. Travellers had lower completion rates for all components of the primary course, especially pertussis and measles. Low completion rates were the result of poor access to immunisation services secondary to mobility, a low priority given to immunisations in general and a widespread rejection of the pertussis vaccine.

Adult health

3. The cardiovascular risk status (as measured by blood pressure, serum cholesterol, incidence of diabetes and smoking) of adult Travellers attending general practice was similar to the local settled population except for the higher smoking rate.

4. Self-reported alcohol consumption of Travellers in this sample was similar to the local settled population, although I would only have been able to detect a very large difference in male consumption.

5. The proportion of Traveller women ever having a cervical smear was less than the local settled population. Mobility, reluctance to have a smear antenatally or by a male doctor and lack of knowledge about cervical smears contributed to this difference.

Health beliefs

6. It was possible to explore Traveller health beliefs through semi-structured interviews, although unstructured interviews or participant observation would be necessary for a deeper understanding of their views. The most important aspects of illness prevention for Travellers were environmental standards and control over mobility.

Primary health care

7. Travellers experienced problems with access to primary care services and a minority of general practitioners stated that they actively excluded Traveller patients. General practitioners in East London reported problems of continuity of care, absent medical records and Travellers not making or keeping appointments.

8. The Travellers' health visitor in Hackney had a wide-ranging role, transcending traditional health visiting and centred on patient advocacy and integration of Travellers into existing primary care services. She was highly regarded by most Travellers as someone to whom they could talk and bring their problems. The main problems the THV faced was a large catchment area, absence of administrative support and too many tasks without a system of prioritisation.

9. A minority of Travellers used their hand-held medical cards in Hackney, but probably not when they travelled in other areas. Most interviewed Travellers thought the records would be useful for some adult patients in specific circumstances and for children.

Taken as a whole, the data from the three parts of this study support my thesis that locally-based research which focuses on Travellers as an ethnic group and examines their relationship to primary health care professionals reveals areas of unmet need and helps to articulate health care priorities. Two issues which were not explicitly part of the original questions were the environmental conditions on caravan sites and the high mobility of a proportion of Travellers.

5.7 Environment & Mobility

5.7.1 Environmental conditions on caravan sites

None of the caravans of interviewees living in Hackney had running water, although on the long-standing "tolerated" site Travellers had an arrangement with an adjoining factory for water via a hose pipe (Table 4.52). This site also had regular rubbish collections and toilets, which other Hackney sites lacked. In Haringey, the official site in Wood Green has complete facilities and their tolerated site also receives basic services, which reflects Haringey's commitment to site provision (Hyman 1990). Poor provision of basic facilities which are taken for granted by most settled people in the developed world, and the health risks which can arise from no running water, toilets or rubbish collection accounts, at least in part, for the priority Travellers gave to environmental over health care issues in the interviews.

My sample of Travellers was not necessarily representative of Travellers in Hackney or in the other two boroughs where our respondents were living, but I know that with the exception of Travellers living on the tolerated site on Gransden Avenue, no Travellers in Hackney had access to water, toilets or rubbish collection on their sites during the period of our interviews: 1989 to 1991 (Environmental Health Department, London Borough of Hackney, personal communication). My findings suggest that access to basic amenities for Travellers in Hackney was even worse than the patchy provision in East Anglia and Kent (Table 2.7). None of the sites in Hackney, temporary or tolerated, complied with the recommendations for Traveller and Gypsy caravan sites formulated by the Council of Europe in 1981 and adopted by the Association of Public Health Inspectors in the U.K. (Sirockin 1988).

I have not studied the effect of environmental conditions on the health of Travellers although Travellers themselves mentioned "gastroenteritis" or "diarrhoea and vomiting" more frequently than any other conditions when asked about the main illnesses their children get (4.4.4d). They attributed the prevalence of these illnesses to dirty sites and poor water supplies (4.4.e). The problem of intestinal infection for Traveller children in Hackney was also highlighted in a retrospective survey of

microbiology results at Queen Elizabeth Hospital. It was found that in 1988-90 one quarter of children presenting with diarrhoea who subsequently had giardia isolated in their faeces and one fifth of those with cryptosporidium were from Traveller families (Thomas and others 1990).

5.7.2 Mobility and ethnic identity

One third of the Travellers who were interviewed had moved more than a dozen times in the previous year and another third had not moved at all in that time, although the term "move" can be ambiguous (see 4.4.3). This differed from the Travellers in Kent, where 72% had not moved in the course of the previous year (Pahl and Vaile 1988). In O'Byrne's (1990) Irish study only 12 out of the 25 families spent all year on the road, the others living mostly in local authority housing. Of the "habitually mobile" families in her study, only one had been on their site for more than a year. Questions about mobility always felt awkward; more than with other questionnaire sections, the interviewer felt she was "prying". This has also been observed by other researchers.

> We are very aware that the data about movements, locations and timings are among the most sensitive parts of the survey: Travellers have many reasons for not wanting outsiders to know their movements. (Pahl and Vaile 1988:201)

Nevertheless interviews in Hackney did reveal a high proportion of involuntary moves in the sample, with repeated evictions from unofficial sites in east and north London. Evictions may have direct detrimental effects on Traveller health, particularly that of pregnant women and neonates (O'Sullivan 1992). Among the Travellers who reported evictions at some point in the past year, most also chose to move for family or economic reasons at other points.

High population mobility is a problem for a health service which has evolved for a largely settled community. Continuity of primary care and availability of medical records is in principle achieved by registration with a general practitioner, but this is based on a fixed address. The mobility of homeless families in temporary accommodation (Golding 1987) and single homeless people (Whaley and others 1989) also present challenges to primary care and may require specially designed services.

A difference between Travellers and these other groups is that mobility for Travellers is bound up with their ethnic identity. This is reflected in the interviews where Travellers tried to explain that they like to move on. For example, one woman told us:

> Might be here today and somewhere else tomorrow. Definitely don't want to be in the same place.

This impulse is captured by Charlie Smith, one of Britain's leading Gypsy poets and human rights activist:

> I get this urge deep inside me
> Like a bull pulling on a drain
> Getting ready to go, pulling me out there
> Through the imaginary bars I feel like a prisoner
> I want to move like I need a drug
> Being tied down's no good for me
> All the places out there I've never seen
> From deep down inside me comes this feeling
> This urge, this draw, this pulling power
> Like the winds, like the sea
> My spirit inside me needs to be free.
> (Smith 1990:44)

Liegois identifies Traveller mobility as a state of mind bound up with ethnic identity.

> Many find themselves in a house or caravan without wheels, but still have the state of mind of a nomad, as they exist in a precarious situation which they consider provisional, one which may last decades, or throughout a lifetime, or may change rapidly...Tent, caravan or house: those concerned do not judge each other in terms of type of housing; they know that it is both functional and provisional and frequently precarious and imposed (Liegois 1987:34).

Voluntary mobility is a cultural and economic choice for Travellers, while involuntary mobility, arising from the shortage of legal caravan sites and a policy of eviction, is the result of a largely settled society's response to Traveller's choice of lifestyle and domicile.

Of the factors related to Traveller ethnic identity which may effect health care, mobility has the largest impact in this study. It overshadows choices about immunisations, cervical smears and even discrimination against Travellers from doctors and other health care providers. On the other hand, none of these factors,

including mobility, are unique to Travellers. It is possible to classify Travellers by their mobility with other mobile groups or by the discrimination they experience with other ethnic minorities or by their low income with other economically deprived groups or by their refusal of pertussis vaccine with groups suspicious of orthodox medicine. Therefore I will conclude by a re-examination of reasons for addressing Travellers as a group in health care research.

5.8 Travellers health and health care research

5.8.1 Traveller-Gypsies: a valid focus for research?

In my introduction I discussed the problem of disentangling class from ethnic differences in health and access to health care. In the United States, where there are no national data on mortality by class, a focus on genetic, psychological and cultural factors obscures poverty, poor housing, occupational hazards and unemployment as aetiological factors (Lancet 1991). Another pitfall in the use of ethnic categories in health care research is the assumption of homogeneity.

> The avowed aim of using a standardised terminology is improvement in the identification of an ethnic group...However the heterogeneity of the population included under the umbrella term undermines the validity of defining it for social research and policy purposes (Gimenez 1989:562).

I started this thesis with a three-fold defence of research on ethnic minority health and health care needs: differential mortality/morbidity, the role of specific health beliefs and problems of discrimination and access to health services. My claim for the usefulness of focusing on Traveller health needs and perceptions does not rest on an assumption of cultural homogeneity, but on Traveller self-identification and exposure to objective forces which distinguish them from other groups. Heterogeneity *per se* does not invalidate either the descriptive epidemiology or the interview results. My findings cover two of the three rationales for ethnic minority health research.

I did not directly address the first rationale - **differential morbidity/mortality** - except in studying cardiovascular risk factors. With the exception of smoking, there was no large difference in cardiovascular risk between the Traveller and control groups. On the other hand, studies which I reviewed suggest that Travellers experience increased morbidity and mortality compared to the settled population. Although some of this difference is secondary to Travellers' economic position (also not homogenous), specific factors such as health care and environmental conditions may be important.

Specific beliefs about the hazards of pertussis immunisation or antenatal cervical smears, about illness aetiology and prevention, or about antenatal care are not exclusive to Travellers. But I found that these views were often expressed in the context of Traveller ethnic identity. It is unlikely that health professionals will be able to influence these beliefs if they do not recognize their relation to identity. It would therefore be pragmatic to focus on Travellers as a group in designing health education intervention.

Discrimination and poor access to services is a recurrent finding in the different parts of my study. A minority of general practitioners stated baldly that they did not accept Travellers as temporary patients in their practices; low immunisation and cervical smear rates partly reflect poor access to preventive services and Travellers themselves spoke about overt discrimination from practices. Independently of explicit discrimination, mobility (enforced and voluntary) creates a specific problem of access to health services for Travellers.

I do not claim that Traveller ethnic identity is a *sufficient* explanation of differential cervical smear, smoking and immunisation rates, or of the health beliefs expressed by the Travellers we interviewed. Yet the particular constellation of mobility, discrimination and health beliefs that emerge from the interviews are part of what constitute Travellers as an ethnic group. This constellation challenges primary care services in Hackney and probably the rest of the United Kingdom. This would still be the case in the unlikely event that sufficient secure sites for Travellers were built

so that all moves were voluntary. Appropriate modification of primary care services requires an understanding of Traveller priorities and choices about health care. For instance, my study shows that direct provision of immunisation services to caravan sites would probably improve the uptake of double antigen and polio but not, in the absence of specific health education, pertussis vaccines. Another specific finding is that direct provision of cervical smears on caravan sites is unlikely to make any impact on cytology rates. Further research on outreach services needs to test these hypotheses and investigate the relationship between use of mobile and fixed services, as has been done for single homeless people in London (Ramsden and others 1991).

5.8.2 Narratives

The interviews with Travellers in this study skimmed across the surface of Travellers' health beliefs. In my desire to cast light on specific epidemiological findings and service questions about access, I had moved quickly to a semi-structured interview method. This had some negative consequences. By focusing on specific health and health care issues, the "space" of the interview became dominated by a medical model and reflected my priorities as a general practitioner. Although many questions were open and respondents were not asked to choose between limited answers, the question-answer mode (and the resource-driven decision not to record interviews) only gave a limited insight into Travellers' *narrative* around health (Brody 1991). My work represents a compromise between a quantifiable questionnaire-based study of a larger group of Travellers which makes even more assumptions about commensurability between medical and Traveller beliefs and a truly ethnographic project without structured questions. This compromise is analogous to that struck in a general practice consultation when both the patient's story and the practitioners' diagnostic agenda are partially accommodated.

From my findings I do not think a structured questionnaire survey of Traveller health beliefs, such as Coulter's (1987) study of the settled population in Oxford, is an appropriate research strategy. An understanding of Traveller health beliefs and perceptions of health care requires more ethnographic data and a qualitative

methodology. My interviews were a step towards a "thick description" of these beliefs (Brody 1991), but were constrained by the preventive health issues I wanted to address. Participant-observation with Travellers, modelled on the work of Okely (1983) would incorporate fewer preconceptions into data gathering and would provide a more direct understanding of Traveller ethnicity, health perceptions and relationships with health professionals.

5.8.3 Community-based research

The exercise in descriptive epidemiology which forms a part of this study is limited by its location in primary care centres. A model for this type of research is Tudor-Hart's (1988) "fusion of epidemiology and primary care" where case-finding or anticipatory care allows the general practitioner to assess specific health needs of the local population. With a largely stable population, the practice list provides a denominator for needs assessment which can be linked to the larger denominator of the local population. On the assumption that "every patient has their own GP" (Tudor Hart 1988:100), practice-based research may be sufficient for the majority of health needs assessment, particularly if the practice list is used to contact people at home. In the case of Travellers in Hackney and other areas, assumptions about near-universal registration or even access to general practitioners are unwarranted.

My sample of adult practice attenders was not necessarily representative of the Traveller population in Hackney. But even this "accessible" sample was not a well-defined stable population, since most were being seen as temporary residents without continuous notes. Tudor Hart's model and particularly its capacity for longitudinal evaluation (Tudor Hart and others 1991) does not easily fit the Traveller population. I could not even make an assumption about the geographical location of Travellers recruited to the study since false addresses were given and an unknown proportion travelled from Haringey, Islington and even Kent and Sussex. With a settled population, general practice is a powerful base for health needs research and the targeting of preventive care for deprived sectors of the community (Marsh and Channing 1988). In the case of Travellers, both research and intervention needs a wider base. The need for some primary care services to be provided on caravan

sites, which I discussed above, has its parallel in research which needs to reach beyond primary care facilities.

A community-based survey which approaches Travellers on Hackney sites would complement my study, although, with the distances Travellers are willing to travel to see a doctor, this would not adequately define the demand on Hackney primary care facilities. Moving research out of practices onto the caravan sites would also not solve the problem of defining a denominator for a Traveller sample, because of the quick turnover on temporary sites. The survey would need to spread data collection through the year since numbers of Travellers and sites fluctuate. The problem of studying men, who are often away from sites during the day will remain. A recent survey of 19 families on a caravan site in West London was only able to include one man in the sample (Riverside Public Health 1992).

Generally a survey is more likely to be well-received by Travellers if it is linked to "normal" health care (analogous to the questions and tests offered during patient-initiated consultations in my study) or the provision of some service. An important difference between a primary care and community-based survey is that the subjects in the former choose to put themselves in a context where health-related questions and interventions are expected. After a study of Gypsies in Sweden, Johansson concluded that "pure" research which just collected data was both methodologically unsound because of limited cooperation from the "subjects", and unethical because it did nothing to improve conditions for a marginalised group (Johansson 1978). Ideally, data collection on caravan sites should be integrated into the outreach work of the Travellers' Health Visitor and form part of an action-research programme which audits the effect of outreach and referral to general practice on preventive health variables. Knowledge about disease risk factors and preventive or screening procedures is sterile without a mechanism for addressing them either on sites or in practices and clinics. Analysis of the THV's activities made it clear that additional research or any other activity cannot simply be added to her workload and will require new resources.

A consensus is forming in favour of ethnic monitoring of health service use (Bahl 1991), although there is still debate about appropriate classification systems (Heath 1991). Systematically collected data would eliminate the need for "one-off" studies targeting, for instance, the immunisation rates of specific groups. This study makes a strong case for Travellers to be included in ethnic origin data sets when these become part of routine health information systems.

Choice of research methods flow from the aims and priorities of researchers as well as their resources. In studying a marginalised community such as Travellers there is an obvious danger that medical and health service research may perpetuate their powerless position vis-a-vis health care professionals and continue to conceptualise them as a problem. Bhopal (1992), in a critique of the chief medical officer's analysis of ethnic minority health needs in the United Kingdom, rejected the "problem-oriented" assumption that lies behind most ethnic minority health needs assessment. He attacked a pre-occupation with differences between groups and argues for a sound understanding of the actual 'practices' of each group. In the course of the research reported in this dissertation, I have moved from a study of differences between samples of Travellers and the settled community to a wider understanding of Travellers' relationship to primary health care. From an initial focus on issues determined by the medical model, Travellers themselves broadened my perspective during the course of the study to include environmental health conditions and mobility.

Future research on Travellers' health care needs should incorporate ethnographic methods and prioritise the early participation of Travellers in setting the *aims* of studies and health care interventions. Health researchers and professionals need to question the

> ...depersonalising categories of power holders - those who seek to control and create order among the unproductive members of politically and economically competitive Western societies... Gypsies' awkward individuality is threatened by control-oriented research methods. In consequence deviance or silence may be their only defence (Hockey 1990:14-15).

Appendix A: Questionnaires to general practitioners and community medical officers

Travellers' health care: General Practitioner questionnaire

Please put a ring around your answer and add any comments on the back. Thank you.

1. Does your practice accept Travellers as Temporary Residents? **Yes** **No**

2. In the last 12 months have any Travellers attended your practice? **Yes** **No**
(If not, please ignore rest of questionnaire but still return it to us. Thanks)

3. What is the approximate number of Travellers seen in your practice?

less than one a month **one a month** **one a week** **more than one a week**

4. Does your practice retain permanent notes for Traveller patients or are consultations recorded on FP19's which are returned to the FPC?

Permanent notes **FP19's** **both**

5. Did you know there is a specialist health visitor for Travellers in your area?
Yes **No**

6. Have you or your partners had any contact with the Travellers' Health Visitor in East London [name of THV]? **Yes** **No**

7. In your experience of providing health care for Travellers do the following issues arise:

Problems of making or keeping appointments? **Often Sometimes Rarely Never**

Lack of continuity or follow up? **Often Sometimes Rarely Never**

Lack of information about past medical history and medication?

Often Sometimes Rarely Never

8. Would you find more information about Traveller culture useful in improving health care to this group? **Yes** **No**

9. Given that you are a GP with many demands on your time, would you be willing to participate in limited project to improve the health care of Travellers, tailored to general practice? **Yes** **No**

Name: Address:

Travellers' health care : Community Medical Officer questionnaire

Please put a ring around your answer and add any comments on the back. Thank you.

1. In the last 12 months have any Traveller children attended your clinic? **Yes No**
(If not, please ignore rest of questionnaire but still return it to us. Thanks)

2. What is the approximate number of Travellers seen in your child health clinic?

less than one a month one a month one a week more than one a week

3. Did you know there is a specialist health visitor for Travellers in your area?
Yes No

4. Have you had any contact with the Travellers' Health Visitor in East London [name of THV]? **Yes No**

5. In your experience of providing health care for Traveller children do the following issues arise:

Lack of continuity or follow up?
Often Sometimes Rarely Never

Lack of information about past medical history and medication?
Often Sometimes Rarely Never

6. Do you find that Traveller parents retain and re-present the child health record cards given at your clinic?
Yes No

7. Would you find more information about Traveller culture useful in improving health care to this group?

9. Given that you have many demands on your time, would you be willing to participate in a limited project to improve the health care of Travellers.
Yes No

Name:

Address:

ENDIX B: BLOOMSBURY HEALTH VISITOR RECORDING CARD

	MON	TUE	WED	THU	FRI
AM					
PM					

NG: _____ 19____

RSONS VISITED		FIRST VISIT					TOTAL	RE-VISIT					TOTAL
		MON	TUE	WED	THUR	FRI		MON	TUE	WED	THUR	FRI	
orn In Current Calendar Year													
Under d but n In endar	Under 1 Year												
	1 Year Old												
	2 Years Old												
	3 Years Old												
	4 Years Old												
	5–16 Years												
	17–44 Years												
	45–54 Years												
	55–64 Years												
	65–74 Years												
	75–84 Years												
	85 Years & Over												
TOTAL													

LOAD BREAKDOWN l Cases Included Above)	FIRST VISIT					TOTAL	RE-VISIT					TOTAL
	MON	TUE	WED	THUR	FRI		MON	TUE	WED	THUR	FRI	
idicapped (All Ages)												
andicapped (All Ages)												
ll Ages)												
ectious Disease — T.B.												
— Other												
eavement												
TOTAL												

RE/CLINIC WORK		TOTAL
of s	Child Health	
	Ante-Natal	
	Family Planning	
	Women's Health	
of ences	Clients Present	
	Clients Absent	
Meetings Attended		
nt	Students	
	Professional Visitors	

OTHER CONTACTS		TOTAL
General Practitioner Surgery		
Hospital		
Other Health Services		
Social Services		
Day Care Centres	Adult	
	Child	
Schools		
Other		
TOTAL		

ARE RIGHTS.

REFERRALS TO:	TOTAL
General Practitioner Services	
Hospital Services	
Paramedical Services	
Social Services	
Other Statutory Services	
Voluntary Organisations	

WORK LOG FOR HEALTH VISITING FOR TRAVELLERS

te: . APPENDIX C: TRAVELLERS HEALTH VISITOR LOG

RT A

te: .....

w long to get there: _____mins, and back (or to next site): _____mins.

mber of caravans on site: Approximate number of children on site:

nilies by name: Number of children seen/total:

eas of work with timing

Advice:

Comments:

Developmental assessments:

Comments:

PART B

Health Centre based:

	Clinical	Admin
A. Telephone calls received (with times):		
Telephone calls made (with times):		
B. Liaison with other health workers:		
C. Liaison with other agencies (eg teachers):		
D. Facilitating use of health centre services:		
E. Correspondence (with time):		

PART C

Tasks left undone:

Comments:

C. Growth monitoring:

Comments:

D. Referral for hospital:

Comments:

E. Arranging GP visits:

Comments:

F. Arranging dental visits:

Comments:

G. Family planning:

Comments:

H. Antenatal:

Comments:

I. Advocacy/liaison (eg mail):

Comments:

J. Minor treatment:

Comments:

Appendix D: Data cards from QEH and practices

Data card for Queen Elizabeth Hospital accident and emergency department

DATA SHEET - TRAVELLERS PROJECT

Does this child have a hand held Traveller Record Card ?
If yes, do not fill in this sheet.

Date of attendance

NAME

PARENTS NAMES

BIRTHWEIGHT

DOB

WEIGHT

HEIGHT (> 2 years)

IMMUNISATIONS 1 2 3

Dip					
Tet				Measles	
Polio				Rubella	
Pertussis				BCG	

TA CAPES FOR PRACTICES

GP R CORD

FEMA E

D ct s initials

Name D B

Date

BP				
Smok s				
EtOH				
Cx sme r				
Cx sm r c m				
Ra m Serum Ch l s l				
Ra d m Bl d S gar				
R be a				
C t ept on				
FP				
Dru s				
A e g es				

GP RECORD

CHILD

Doctors init als

N me DOB

Date

Birthweight

Immu isati s 1 2 3

D p							
Tet						Mea es	
P o						Rube la	
Pertuss s						BCG	

M d cation

A ergi s

GP RECORD

MALE

Doctors initials

Name DOB

Date

BP				
S k s				
EtOH				
R d m Serum Cho este ol				
Random B ood Sugar				
D u				
A s				

Fam ly H sto y

APPENDIX E: HAND HELD MEDICAL RECORDS

Travelers Project
Dept. of General Practice & Primary Care
St Bartholomew's Hospital Medical College
FREEPOST
London EC1B 1PL

CONTACT ADDRESS

PRESENT LOCATION

HEALTH RECORD

(Use for Women only)

To aid continuity of health care, this person carries her own health records.

If you see this person for health care, please record the details in this document or give an address or telephone number where such details can be found.

NAME

DOB

CHILDREN (No.)

Pregnancy History (if relevant)

Women's Health and Screening Tests

	Date	Date	Date	Date
BP				

Regular Medication

Allergies

DATE PROBLEM (Name of consultant & hospital if relevant) OUTCOME

GP/HV ADDRESS PHONE

LOWER CLAPTON HEALTH CENTRE
36, LOWER CLAPTON ROAD, E5.
986 7111

F

RESPONSE CARD

LC

Dear HV/Doctor

We are studying the use of hand held record cards. If you see the person named on the facing record sheet, did you find the information on this card useful ?

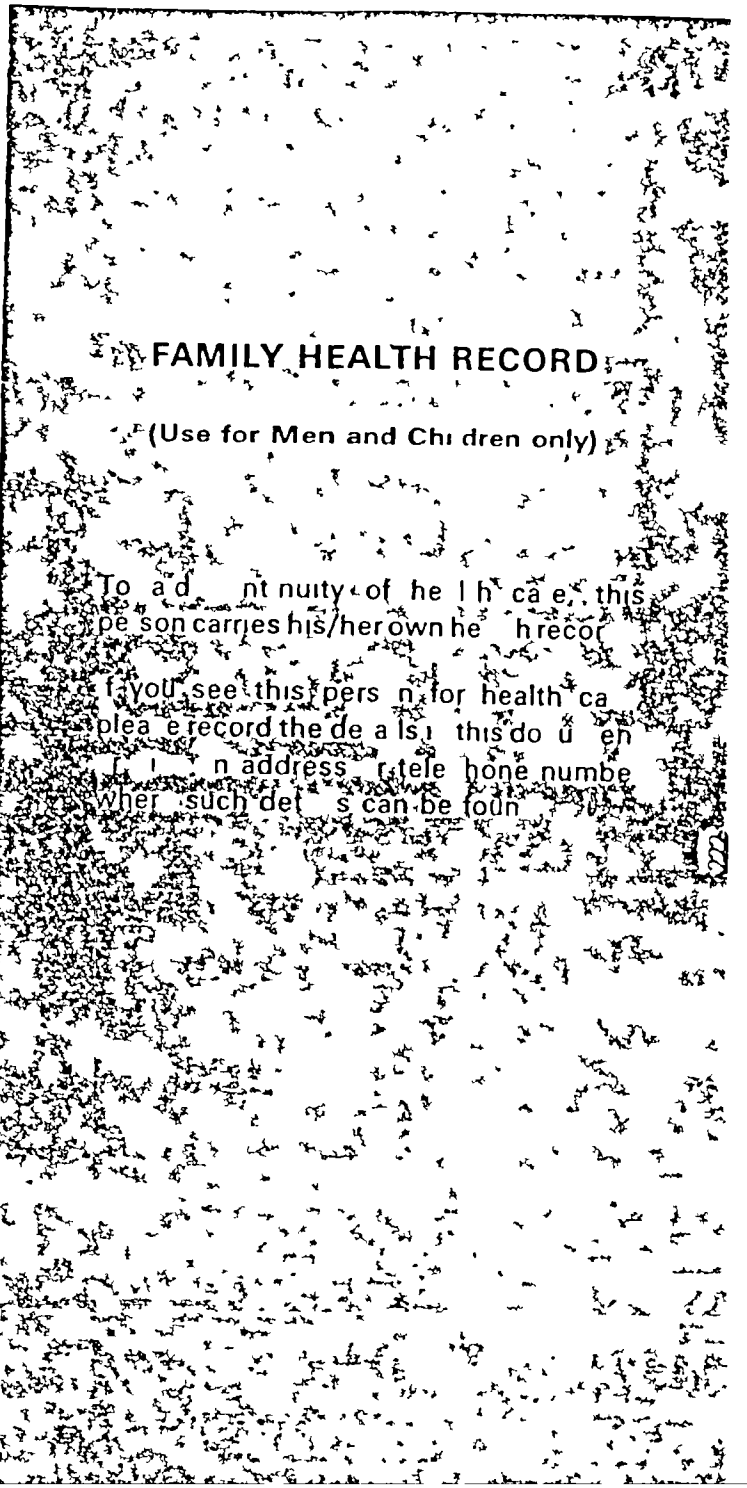
YES NO

Comments/Suggestions

221

Please send this card back to us (no stamp needed).

GP HV ADDRESS PHONE



FAMILY SHEET

	NAME	DOB	FAMILY HISTORY Main health problems
Mother			
Father			
Children			

NOTES
(Special points you feel are important)

PRESENT LOCATION

CONTACT ADDRESS

Travellers Project
Dept. of General Practice & Primary Care
St. Bartholomew's Hospital Medical College
FREEPOST
London EC1B 1PL

INDIVIDUAL SHEET
(Use for men and children only)

NAME

DOB

IMMUNISATION

	Primary			Boosters
	1st	2nd	3rd	
Dip				
Tet				
Polio				
Pertuss				
Measles				
Rubella				
BCG				

Screening tests

BP				
Date	Date	Date	Date	Date

Regular Medication

We are studying the use of hand held record cards If you see the person named on the facing record sheet, did you find the information on this card useful ?

YES NO

Comments/Suggestions

Your name & address !

Please send this card back to us (no stamp needed)

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Appendix F: Possible further investigation of Traveller health beliefs

At the request of my examiners, I have added this appendix elaborating on methods for further investigation of Traveller health beliefs.

In the interview part of my study, there were several instances of informants referring to themselves *as a group* not accepting preventive health care interventions, particularly pertussis immunisation (p.129-130) and smears before the first pregnancy or during the ante-natal period (136-137). This led me to a tentative observation that Travellers' views about preventive health care and also about illness aetiology and prevention were often expressed in the context of ethnic identity. Specifically in the case of the pertussis vaccine I hypothesized that persistent rejection of this vaccine by the majority of Travellers may have become part of the symbolic boundary between them and the settled population (p.162). Ambivalence about other vaccines and stricter criteria for the acceptance of cervical smears may also constitute part of this boundary, which becomes "embodied" in specific taboos.

I have already discussed Okely's interpretation of pollution beliefs as part of an ethnic boundary for Traveller-Gypsies (p.31). The larger theoretical framework for my hypothesis lies within the domain of medical anthropology, where there is a burgeoning literature on the relation between experiences of the body (in health and illness) to group or ethnic identity.[1] In this context, Travellers' selective acceptance of preventive health interventions, particularly those which involve penetration of the body, can be seen as resistance[2] to a dominant culture.

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[1] Lock M, Scheper-Hughes N. A critical-interpretive approach in medical anthropology:rituals and routines of discipline and dissent. In Johnson TM, Sargent CF. *Medical Anthropology:contemporary theory and method.* 1990.New York:Prager.

[2] Martin E. *The Woman in the body: A cultural analysis of reproduction.* 1987. Boston:Beacon Press

What are appropriate methodologies for clarifying the relationship - if any - between Travellers' views about and experiences of preventive health procedures and their ethnic identity? Qualitative methods will be required, as these can focus on the *meaning* people ascribe to some set of circumstances or phenomena.[3] Particularly appropriate is a hermeneutic method which aims to generate a thick description, relying on exemplars and paradigmatic cases to elicit and interpret the meaning of lived experience.[4]

One approach would be a series of in-depth interviews with a purposeful sample of Travellers, ensuring adults from different family groupings. The interviewer would eschew abstract questions about why specific procedures were accepted or not accepted and, instead attempt to elicit accounts of encounters with health professionals where these procedures were offered to the informant or their children. Mention of group identity or generalisations about what Travellers do in these situations would be explored in depth. If permitted by the informants, interviews would be taped, transcribed and submitted to a formal content analysis: developing an organising system, segmenting data and making connections.[5] A problem with these interviews, if not performed in the context of participant observation, is the risk of hearing an artificial discourse in response to the interviewers' presence as well as missing the chance to observe Travellers in their encounters with health professionals. In a recent work, Okely reflects on the "intangible inner experience" which is as much part of the knowledge acquired from field work as the examination of "outside categories".[6]

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[3] Lincoln YS. Sympathetic connections between qualitative methods and health research. *Qualitative Health Research* 1992;2:375-91.

[4] Wilson H and Hutchinson S. Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research* 1991;1:263-276.

[5] Tesch R. *Qualitative research.* 1990. New York:Falmer.

[6] Okely J. Anthropology and autobiography: participatory experience and embodied knowledge. In Okely J, Callaway H. *Anthropology and Autobiography.* 1992. London:Routledge.

A less conventional qualitative method which might be appropriate is the focus group interview.[7] This consists of a guided in-depth interview of a relatively homogenous group purposefully selected by the researcher to address a specific topic. Advantages of this method include the disclosure of "rich" information from interaction between the participants and the changed power relation between interviewer and informants. It may overcome some of the artificiality intrinsic to the individual interview method described above. As with individual interviews, the conversation is transcribed and formally analyzed. To date there is little experience of this method with ethnic minority groups. A recent study of older Hispanic women in Arizona used a focus group method to explore barriers to breast cancer screening.[8] The findings partly confirmed a larger questionnaire-based survey study, but also revealed new insights about how this group of women experienced the health care system. The willingness of many Traveller women in my study to participate in groups to discuss health issues (p.128) suggests that this maybe an appropriate method

The notion that selective acceptance of cervical smears and immunisations was linked to the constitution of ethnic identity appeared in the "margins" of the semi-structured interviews in my study. Both of the methods I have outline to pursue this question would allow a researcher to determine whether this is an incidental finding with little explanatory power or whether it genuinely helps us understand Travellers' view of health care.

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[7] Basch D. Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Education Quarterly* 1987;14:411-448.

[8] St Germain MA, Bassford TL, Montano G. Surveys and focus groups in health research with older Hispanic women. *Qualitative Health Research* 1993;3:341-367.

The politics of Traveller health research

GENE FEDER

Travellers are one of the oldest ethnic minorities in the British Isles. Their history is marked by active persecution and they remain a marginalised sometimes beleagured community. Why study their health status and access to health care? What are appropriate methods? What political dilemmas emerge?

My personal motivation for health research with Travellers stems from frustration about the inadequate level of primary care for Traveller patients in East London, my perception of higher morbidity among these patients and the blatent discrimination Travellers experience in all spheres of life: from health care to housing to leisure, exemplified by the 'No Traveller' signs on most Hackney pubs. When I turned to the literature on traveller health and health care, there was little research to be found. There are a few epidemiological studies and some interesting articles written by health workers, particularly health visitors, who have set up Traveller health projects. There was practically nothing from within general practice and, even worse, a lot of anecdotal evidence that general practitioners actively discriminate against Travellers by not accepting them as patients.

With funding from a NE Thames Regional research scheme I am working with a research assistant on Travellers' health. We have four aims: (i) identification of practices or hospitals who see a significant number of Travellers and a questionnaire to all practices in East London enquiring about their attitude toward Traveller patients; (ii) understanding of child and adult health risk factors and uptake of preventive services (immunisation and cervical smears); (iii) development and evaluation of a hand-held medical record card; (iv) understanding of Traveller health perceptions and views on health care provision.

Previous Traveller health research

Previous epidemiological studies left a number of unanswered questions. The one study of adult health (done in Boston, Massachussets) suggested an epidemic of diabetes, hypertension and hyperlipidameia, but the sample was largely self-selected and extrapolation of the resuts to other Traveller groups was questionable. Two studies of immunisation status and maternal/child health in the UK showed low immunisation rates and high perinatal and maternal morbidity and mortality.

One of these studies, from East Anglia, was methodologically flawed and revealed a political dilemma at the heart of research on Traveller health. This dilemma, which is inherent in any research 'on' a community, is how to present results such as high morbidity or low immunisation rates in a constructive way. When the ruling ideology in much of health promotion discourse is individualistic (with an emphasis on personal responsibility for health), 'negative' findings can be used to portray Travellers as irresponsible and feckless. The report was criticised by Traveller organisations both for its methodological errors and the negative portrayal of Travellers' attitudes towards health and health care. It was withdrawn from wider circulation by Save the Children Fund (its sponsor) and, although still available for academic purposes, comes with a qualifying commentary. One lesson from this episode is that the design of research and the promulgation of findings must involve the Traveller community.

Consultation

We made consultation with the Traveller community a priority. But what is the Traveller community? There are national Traveller organisations, but partly because of the differences between Scottish, English, Welsh and Irish Travellers, they do not necessarily represent the view of Travellers in East London. Consulting the national organisations at the design stage, which we did, is no substitute for local consultation. Even here there were uncertainties: those Travellers who I had come to know were inevitably those who were easier to consult, but in crucial ways were not representative of Travellers in East London or even in Hackney.

Another paradox was that on specific questions of method or priorities, Travellers we consulted often did not want to express an opinion, deferring to us on the grounds that they were sure we knew best. Finally, when we did get clear views, they did not always work well in practice. For instance, in designing a handheld record card we acted on the views of Traveller women who felt strongly that they wanted a separate card from their husbands and children. In practice, we found that most women kept their card in the same folder as the family card and that the two separate cards have been very confusing for participating doctors, undermining their effectiveness!

This account is not an argument for avoiding consultation, but reflects the problems faced in making it a reality. I'm sure that we did not devote enough time to consultation partly because of wanting to 'get on' with the research: only later did we realise that consultation was an integral part of the research itself!

Beyond the medical model

Originally we saw the interviews with Travellers in the 3rd year of the research as a way of throwing light on the epidemiological data on immunisation rates, smoking rates, cervical smear uptake, presenting complaints, blood pressure, etc. For example, the low uptake of pertussis immunisation might have a specific cultural explanation which would influence the design of health promotion material. This approach starts from a simplistic medical model and prioritises certain medical concerns, such as immunisation and cardiovascular risk factors. Luckily, instead of using questionnaires which embodied these assumptions, we started with unstructured interviews, lasting 1–2 hours. This allowed us to hear what Travellers saw as *their* priorities: secure, safe sites, with adequate sanitation and water supplies and freedom from harassment. Travellers are more concerned about not being moved from their current site and that decent toilets are installed, than about increased immunisation or cervical smear uptake. Moreover, they enjoined us to support them in their fight for decent sites.

In an abstract way – as a subscriber to a largely materialist epidemiology – I was aware of the importance of living conditions for good health, but somehow in the original design of the research I had become entrenched in the medical model and mesmerised by health *care* issues. As a doctor, these are obviously issues I feel comfortable with and Travellers we have interviewed do not deny their importance. They simply feel that site security and environmental conditions are a greater priority. One could argue that if my original medical model had been more sophisticated (ie. if it included environmental aetiologies) there would be no dissonance between my priorities and those of Travellers.

My point, though, is a wider one: our mistake was not the adoption of a certain medical model, but setting our priorities for resarch *before* entering into a dialogue with Travellers. Although we consulted on methods, we did not consult on aims. Instead of interviewing Travellers about their health concerns in the final year of the study, we should have done it in the first year. I'm not suggesting we would have avoided epidemiological data or the issue of access to health care, but that Travellers' concerns would have figured more largely in deciding what kind of data we needed to collect.

Why collect data at all?

Whether the data are environmental health evaluations of sites or rates of smoking or perinatal mortality, what use do they have other than allowing the authorship of academic papers? Surely they can be used as support for the provision of better sites, better health promotion and better health care, respectively. There are several arguments against this simple supposition:

(i) There is a danger that Travellers will be labelled as unhealthy, which with the prevalence of victim blaming in our culture, may further isolate them. Migrants and nomads from many cultures are traditionally blamed for spreading illness. Travellers on a site in South East London were attacked by local residents with petrol bombs and air guns because they were thought to have polio.

(ii) Evidence for increased morbidity should not be necessary to argue for access to good health care and preventive services. Travellers have a right to these services as any other community in our society. They emphatically do not want to be treated as 'special case'.

(iii) There already is enough evidence for poor health care provision and environmental hazards for action to be taken. Energy needs to go into campaigning, not research.

I do not have any easy answers to these criticisms of the kind of research we're doing. Nevertheless, I think that information about morbidity, risk factors and access to care for a *local* community can help to target services. The challenge is to present the data in contexts where it will not be misconstrued either as a form of labelling or special pleading. I certainly agree that we should not wait for more research to take action on the health needs of Travellers and through our research we have become involved in campaigning before we have finished analysing results. Certain data probably should not be released without challenging its implications; for example, the low immunisation rate should not be used as a further excuse for general practitioners not to accept Travellers onto their lists for fear of not reaching immunisation targets. Family Practitioner Committees must find methods to encourage general practitioners to take on Travellers.

The politics of health research with Travellers is complicated, as with any minority community, particularly if one of the researchers is a member of the majority community and a male doctor. Most of our informants are women. I still have doubts about the work we are doing in East London. It sometimes seems irrelevant to the empowerment of Travellers in the sphere of health and health care which remains the underlying goal. On the other hand, Travellers themselves identify the research as worthwhile and have supported our work, if only because it represents some effort on *their* behalf regardless of ultimate outcome.

Acknowledgements

Thanks to Jan Savage for comments on this article and Theresa Vaclavik for collaboration on the research.

A bibliography of research on Travellers' health can be found in:
Feder, G. Traveller gypsies and primary care. *Journal of the Royal College of General Practitioners* 39, 425–429, 1989.

For policy and campaign proposals around Traveller maternal and child health see:
Durward, L. *Traveller mothers and babies. Who cares for their health.* London: Maternity Alliance, 1990. (Available directly from Maternity Alliance, 15 Britannia Street, London WC1X 9JP).

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Traveller mothers and babies

Health authorities need to provide better care

There are at least 12 000 traveller gypsy caravans in Britain.[1] This community of over 60 000 people belongs to one of Europe's oldest and most marginalised ethnic minorities.[2] Like other groups on the edge of our society, including the homeless,[3] they have difficulties gaining access to health care.[4,5] Despite the introduction of specialist traveller health visitors in some health authorities[6] many travellers still do not benefit from regular medical services, and many authorities have no policy on health care for this community.[7]

A recent report from the Maternity Alliance took a broad view of the maternal and perinatal health care provided for travellers.[8] The fact that this group suffers poor health has already been well described.[9,10] To its credit the Maternity Alliance did not go over that evidence again but instead looked at possible underlying factors. The report reminds us that the health of pregnant travellers and their babies depends partly on the facilities and environmental conditions of caravan sites: that is, the presence or absence of hot and cold running water, electricity, regular rubbish collection, and functioning toilets. Past studies have described the poor facilities found particularly on unofficial sites,[9,10] and the Maternity Alliance claims, firstly, that many sites are still inadequate and, secondly, that the number of sites provided is insufficient for the traveller population. The report emphasises another factor that undermines maternal health and also jeopardises the provision of antenatal and perinatal care—the forcible eviction of traveller families from unofficial sites. "The best and most accessible antenatal care is of little avail if a mother is continually moved from one health district to another."[8] Travellers need secure and safe stopping places.

The Maternity Alliance prompted the Association of Metropolitan Authorities to survey its members about provision for traveller families. The survey found that, of 43 responding authorities, almost a third would evict pregnant women "close to birth," and more than a third would evict pregnant women or mothers with a newborn baby. At least the metropolitan authorities replied; the Association of County Councils and the Association of District Councils "seemed unwilling to give any priority to investigating their members' policies with regard to Traveller mothers and babies."[8]

The report moves beyond a critique of health and local authority policy (or apathy) towards travellers to positive recommendations. For local authorities these range from the development of "non-harassment" policies for pregnant or newly delivered mothers on temporary sites to the provision of basic environmental health amenities and regular liaison with health authorities and representatives of local travellers. The report calls on health authorities to include travellers' needs in the planning of services, to name a person to coordinate information relating to travellers, and to liaise regularly with local authorities, family practitioner committees, and travellers themselves. Such recommendations are more than pious hopes: the report describes various health and local authority initiatives in Essex, Medway, east London, East Anglia, Sheffield, and Liverpool as examples of good practice. They should encourage other authorities to take the plunge.

One of the unresolved issues for travellers' health care is the balance between specialist "outreach" services such as mobile health caravans and integration into existing general practice and community health services.[11] Integration is hampered by discrimination on the part of some health care providers as well as the mobility of travellers, their lack of postal addresses for appointments, and their low literacy rate. Travellers also have different cultural perceptions of health and illness from most health workers.[11] These barriers to health care require imaginative solutions, such as the use of hand held medical record cards and mutual education of travellers and health care providers. Sadly, the new contract for general practitioners may inadvertently discourage the registration of travellers, especially in practices struggling to meet immunisation and cytology targets.

We need research on travellers' health needs and health perceptions as well as evaluation of interventions such as hand held record cards, educational initiatives, and increased liaison between different agencies concerned with travellers' health. Already, however, we know enough for authorities to take action. The government's new health service legislation charges district health authorities with responsibility for assessing the health needs of their populations and purchasing the appropriate services. The Maternity Alliance report is a timely reminder to health authorities not to overlook the needs of travellers.

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their psychiatrists easy to talk to, many were not satisfied with explanations about their condition, and most thought that they had not been given enough information about their treatment. Patients complained that they had not had enough time alone with their psychiatrist. Surely all these are arguments in support of a psychiatrist being a personal physician able to have a therapeutic relationship with an appropriate and not excessive number of patients. This can be achieved only with an increased number of consultants.

Since writing to the *BMJ* Ms Hepplewhite has stated that she approves of psychiatric services in Italy and that the number of trained psychiatrists per head of population in Italy is considerably above that in the United Kingdom paper presented at annual meeting of Royal College of Psychiatrists, Brighton, 1991 . It is a pity that she does not work with the professional bodies in trying to obtain more resources for mental health to improve facilities in all areas, including social services provision, consultant psychiatric staffing, community psychiatric nursing, and other community and hospital developments.

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Licensing laws and drinking

SIR,—There is a temptation, when a survey does not say what was hoped and expected, simply to dismiss its findings. Sadly, this is the line adopted in the news report of *Drinking in England and Wales in the Late 1980s*. This survey shows that the changes to pub opening times made in the Licensing Act of 1988 have not had any great effect on average consumption levels. Baroness Hooper, a junior minister at the Department of Health, was quick to lend her justification to the Home Office's changes, expressing her delight that the changes had not led to increased drinking.

Baroness Hooper went on to mention the government's targets for alcohol consumption as set in the green paper *The Health of the Nation*. This document proposes a reduction in the numbers of people drinking more than the sensible levels to fewer than one in six men and one in 18 women. The government has drawn up its own criteria for tackling alcohol abuse. How have the changes to licensing laws advanced the achievement of these aims?

The answer, it seems, is scarcely at all. *Drinking in England and Wales in the Late 1980s* shows that the number of people drinking over sensible levels—21 units a week for men and 14 units for women—fell slightly, from 24% to 22% of men and from 9% to 7% of women. The numbers drinking above safe levels—50 units for men and 35 units for women—remained constant

The truth of the matter slowly begins to emerge from the figures. The changes in the licensing laws have not altered most people's drinking at all—they are neither popular nor well used. But go to your local pub on a weekday afternoon and there you will see the people who are "benefiting" from the Home Office's changes: the heavy drinkers. Average consumption among heavy drinkers has increased from 56·8 to 58·9 units per week for men and from 37 0 to 37·4 units for women.

When the survey looked at who visited pubs during the new opening hours the pattern was repeated. Eight per cent of all men had visited a pub on a weekday afternoon in the week before the survey; 32 of heavy drinking men had, and 36 % of all men had been in a pub at 11 pm in the week before the survey; a massive 88% of heavy drinking men had.

The *BMJ*'s report of *Drinking in England and Wales in the Late 1980s* chose to focus on the inadequacies of the survey because of the realisation that the problem of alcohol misuse is simply too vast to be hidden behind bland headline figures—and so it is. But what the survey does show is that, while most people are ignoring the new permitted hours, heavier drinkers have taken the changes on board and are drinking to their heart's content.

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Uptake of cervical smear testing among travellers

SIR,—Drs Domhnall MacAuley and Ursula Anderson discuss problems of cervical smear testing among travellers and of assessing uptake in this mobile community.

In a study of health care of travellers in Hackney, east London, we included assessment of cervical smear state in 61 consecutive traveller women presenting to two general practices between August 1989 and December 1990 and compared uptake with prospective matched controls for age registered in the same practices (table). We considered women eligible for a smear if they had had sexual intercourse. The relatively high proportion of women who had never had a smear 36% *v* 14% of controls) is disappointing. Of the 22 traveller women who had never had a smear, nine were receiving antenatal care at the time their smear state was recorded. This failure to take a smear in pregnant traveller patients may be due to late booking and reluctance to have a smear while pregnant. Eviction from caravan sites of mothers with newborn babies[2] before a postnatal check results in another missed opportunity for a cervical smear test, as well as depriving the mother of postnatal care and the baby of early health care.

Proportion of eligible women who had never had a smear test

Group	Mean age	No % never had smear
Travellers n=61	29	22 36
Controls n=65	30	9 14

Difference=22% 95% confidence interval 8% to 37%) $\chi^2=8·4$, df=1, p=0·0038.

This data is based on a sample of traveller women in contact with primary care services and may not be representative of all traveller women in Hackney, whose cervical smear testing rate is probably lower.

As a follow up to the cervical smear survey, 22 traveller women were interviewed on caravan sites and in the practices about their views of health and health care. Sixteen answered questions about cervical smear testing. Only six of them were aware that the smear test was used to prevent carcinoma of the cervix or had any connection whatever with cancer; 12 said that they would be more likely to have a smear if it was performed by a woman doctor or nurse. Four said they would be more likely to have one if the facility was available on their caravan site, but most of the women were strongly opposed to this

Appropriate health education about smears for traveller women and offering opportunistic smears—particularly by women doctors and nurses—may increase uptake. Beyond these measures, if women who do not have contact with primary care are to be reached then health authorities need further to develop outreach services to caravan sites through health visitors.

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MRCGP: examining the exam

SIR,—Mr Miles Irving reports that the English FRCS examination has been under expert educational scrutiny over the past two years. This enthusiasm for professional advice is welcome news Coupled with the surgeons' commitment to glasnost "no part of our examination, or the statistical information concerning it, is regarded as confidential" it will doubtless move to overcome the difficulty which many inquirers have experienced in obtaining technical information from royal colleges about their examinations I have some gems of letters on file from those who bother to reply, collected over the years . Indeed, many colleges are still quite unable to provide very basic statistical information about their examinations.

Draft minimum information set which candidates could expect to receive about a medical examination

Content:	Aims, objectives, specification of scope of content
Format:	Description of types of test used; examples of questions where possible, past papers
Length.	Time for each component, number of questions in each written paper
Marking	Scoring system for MCQs including scoring for items receiving incorrect response Statement about qualities rewarded in other papers, use of marking schedules provide example For viva voce, clinical examinations, OSCEs objective structured clinical examinations ; description of examination process, its focus and marking system
Quality control.	Dual marking; training and monitoring of examiners
Manipulation:	Any statistical standardisation or weighting of components, how these are combined, how borderline candidates are reviewed
Pass or fail	Requirements for example, pass or minimum score in each paper, pass in summated overall mark
Appeals	Mechanism for appeals
Outcomes	Pass rate overall and for indigenous first time takers, reliability of each examination component for example, coefficient α

So can educational researchers and prospective candidates expect to see a full report on the Royal College of Surgeons' fellowship examination similar to that from the Royal College of General Practitioners describing the nature and findings of the educational scrutiny and detailing developments?[4] Would the Royal College of Surgeons and other colleges agree to provide a set of minimum information on their examination see figure for suggestion ? And will we shortly be reading a paper in the *BMJ* called "FRCS: examining the exam"?

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Traveller gypsies and primary care

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SUMMARY. Traveller gypsies have resided in the British Isles for over 500 years, making them one of our oldest ethnic minorities. They experience widespread prejudice and discrimination from the settled population. In the sphere of health care the marginalization of traveller gypsies has resulted in poor access to services and relative neglect of their health needs. In this paper the health of traveller gypsies is reviewed from the perspective of primary care, and the role of general practitioners in improving health care for this community is discussed.

Introduction

THE first record of gypsy groups in the UK dates from the early sixteenth century and their origin is still the subject of ethnographic debate.[1,2] There are four distinct traveller gypsy groups in the UK,[3] but they are geneologically and linguistically related:

Group	*Language*
North Welsh Kale	Inflected dialect of Romanes
South Welsh and English Romanichals	Creolized dialect of Romanes
Irish Pavees or Minceirs	Gammer which mixes middle Irish backslang (Shelta) with English and Romanes
Scottish travellers	Cant which combines creolized Romanes and Gammar vocabulary

The travelling gypsy population has always been heterogeneous, changing as the result of migration and interchange with settled communities. The longstanding myth of the true or pure gypsy as distinct from other traveller groups is fallacious, but useful to local authorities who want an excuse not to provide services to encamped traveller gypsies.[4]

The caravan site act of 1968 used a broad definition for traveller gypsies: 'Persons of nomadic habit of life whatever their race or origin', but this ignores their cultural distinctiveness. Wibberley[5] coined a more specific definition after wide consultation (including traveller organizations) when he reviewed the working of the caravan site act:

> 'Nomadic families who by reason of their lifestyle habitually travel to sell the products of their self employment and to pick up casual or seasonal work, and whose only or main residence is a caravan or tent for which they have no permanent site'

There are approximately 10 000 gypsy caravans in the UK and, assuming a minimum of three children per family, at least 50 000 traveller gypsies. Although Wibberley's definition may be appropriate for planning caravan sites, it is still inadequate for defining the whole traveller community. Oakley argues that the traveller identity derives from lineal descent reinforced by specific cultural choices.[1] This definition includes the approximately 48 000 gypsies who live in houses but still share traveller cultural values and, to some extent, languages. The total population of travellers in the UK is thus approximately 100 000, clustered mainly in East Anglia, Kent, Wales, Scotland, London and urban areas in the Midlands.

Although traveller gypsies identify themselves as a distinct ethnic group, this is not yet universally recognized. For example, a judicial ruling in June 1987 that a landlord was not contravening the race relations act by displaying a 'No travellers' sign was only overturned in the court of appeal in July 1988.[6] Traveller gypsies are now protected under the race relations act and can take legal action if discrimination occurs.[7] The failure to acknowledge traveller gypsies as an ethnic minority is also obvious in accounts of multi-cultural health care, where they are completely ignored.[8]

Why is the definition of 'traveller gypsies' important for health care providers? First, research on traveller gypsies' health and planning of services requires criteria for defining the traveller population. Secondly, recognition of traveller gypsies as an ethnic group may lead to better understanding of their perception of health, illness, prevention, and the role of health services.

Health of traveller gypsies

Although there are approximately one million gypsies in western Europe, 2.5 million in eastern Europe and 500 000 in the USA, there is a dearth of research into their health status.

In the UK there is no national mortality data for gypsies because 'traveller gypsy' is not an occupational category, nor has there been a prospective morbidity study, which would be difficult to organize in such a mobile population. All that exists are anecdotal reports from doctors or health visitors working with travellers, a few small studies of specific health problems and two retrospective studies of child and maternal health. These accounts suggest higher morbidity rates and earlier mortality than among the settled population.

Maternal and perinatal health

One of the earliest reports of serious perinatal problems came from a general practitioner and health visitor in Sheffield who set up a travellers' health project. They recorded a cluster of six perinatal deaths out of 12 births to traveller women between January and August 1982 (Heller T, Peck B, unpublished report).

Systematic data on maternal and child health were first collected in an East Anglian study sponsored by the Save the Children Fund[9] in which 265 traveller mothers were interviewed about their obstetric history, children's health and use of health services. A perinatal mortality rate of 142.4 per 1000 births, a stillbirth rate of 113.9 per 1000 and an infant mortality rate of 53.6 per 1000 were reported. The report was heavily criticized on methodological and political grounds.[10] It was also criticized by traveller groups for stigmatizing their community as a 'special case' with an unhealthy lifestyle and poor motivation to use health facilities. However, the study led to an excellent conference[11] where many of the issues of traveller gypsies' health were clarified.

In a study in Kent by Pahl and Vaile,[12] 263 traveller women were interviewed. The sample included a high proportion of the target population but there was a problem of data reliability, since there was no way to verify the information obtained by self reporting. The perinatal mortality rate was found to be 16 per 1000 births, the stillbirth rate 12 per 1000 and the infant mortality rate 17.5 per 1000. Although considerably lower than the

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rates found in East Anglia, these results are still worse than regional and national rates, with the stillbirth rate showing the greatest difference (national rate 7.2 per 1000). Pahl and Vaile maintain that a detailed perinatal audit is necessary to explain the difference between the rates in East Anglia and Kent. Such a study would also help explain the difference between the rates in both studies and in the settled population.

Pahl and Vaile found a higher proportion of low birthweight babies (less than 2500 g) among Kentish travellers than nationally (12.8% compared with 6.9%). They also found that stillbirth and infant death rates were higher for mothers on private and unauthorized sites than on local authority sites. Another clue to the higher mortality rates is a correlation with increased mobility, which is particularly worrying in the light of a report by the Association of Metropolitan Authorities (unpublished, 1988) showing that 16 authorities would evict pregnant women from unauthorized sites and 13 would evict women close to birth.

Child health

The age structure of the traveller gypsy population throughout Europe differs from the settled population in that approximately 50% of travellers are under 16 years of age.[3] Large families are the norm; in Sheffield in 1982 28% of travellers had more than six children (Wilson G, unpublished report, 1987). In traveller culture child care has a high priority, not only among women, but unfortunately poor environmental conditions and difficult access to health care lead to a relatively high child morbidity.

In 1979 Sampson and Stockford[13] observed a low level of immunization among traveller children and an increased rate of polio and less serious infectious diseases, as well as an increased accident rate. Pahl and Vaile's study in Kent showed that 11% of under five year olds suffered from serious injuries, most commonly lacerations, scalds and burns.[12] Their data on serious illness is difficult to interpret because uniform criteria were not used for judging the severity of illness episodes. The Kent study also included immunization rates, and a comparison with the rates found by Linthwaite in East Anglia[9] and a study in Walsall[14] is shown in Table 1. Pahl and Vaile point out that epidemics of infectious diseases have not been reported among traveller gypsies despite the low immunization rates. They speculate whether this is due to poor reporting of episodes — unlikely in the case of polio, diphtheria and tetanus — or to the relative isolation of traveller communities. A Scottish study suggests an alternative explanation (Riding M, MSc thesis, University of Glasgow, 1985). In a sample of 109 travellers aged five to 61 years the immunization rate was low: 56.0% had no recollection of any immunizations. However, 83.5% had antibodies to polio, 84.0% to diptheria and 50.5% to tetanus (about equal to the settled population, although traveller occupations, such as farmwork and scrap metal dealing, put them at greater risk of tetanus). The study also picked up a high exposure rate to hepatitis A. A curious aspect of this study is the conclusion that 'the general population should not be apprehensive about the development of well run permanent sites in their locality'.[16] This reflects society's generally negative and fearful perception of travellers. As Hussey points out, studies of nomads worldwide often take as a premise the potential risk of infection to the settled community (Hussey RM, MSc thesis, University of Manchester, 1987).

Although the Scottish study gives some reassurance about the consequences of a low immunization rate, this is still an important issue in the health care of travellers, especially as the level of immunity in the UK traveller population as a whole may not be as high as in Scotland. There are anecdotal reports of an increased pertussis and measles morbidity among traveller children (Dodge L, personal communication).

Table 1. Number of traveller children vaccinated by end of second year as a percentage of total born compared with figures for all children in England.

	Percentage completion of vaccinations			
	Polio	Diphtheria/ tetanus	Pertussis	Measles
Kent[a]	24	24	10	14
Walsall[b]	20	20	5	12
East Anglia[c]	7	9	0	12
England (1984)[d]	84	84	65	62

[a]Ref 12. [b]Ref 14. [c]Ref 9. [d]Ref 15.

In Ireland, a prospective study of 108 traveller children aged between two and 13 years showed a consistent height deficit compared with children from the settled community.[17] However, no conclusion about environmental or genetic contributions can be drawn, especially as parental height was not measured. A retrospective Irish study showed decreased head circumference in the first year of life in traveller children admitted to hospital compared with non-traveller children, although the study was flawed by the absence of a hospital based control group.[18] There is no comparable data from the UK, but these studies are relevant to traveller child health care in this country because of the relatively large influx of Irish traveller gypsies over the last 20 years.

Another cause for concern is evidence for an increased risk of autosomal recessive disorders among traveller children because of intermarriage and a high consanguinity coefficient. In a study of 1200 traveller gypsies in south Wales, Williams and Harper found a phenylketonuria incidence of one per 40 compared with a one per 6000 in the settled population.[19]

Among accounts of traveller child health there are a number of optimistic signs. In the Walsall study,[14] where environmental and physical risk factors were increased for traveller children compared with other children, there was a lower incidence of non-accidental injury among travellers. In Roehampton, after an unvaccinated traveller baby developed polio, travellers welcomed an immunization initiative by the local department of community medicine. With the help of a Romany Guild spokesman, a 92% uptake of oral polio vaccine was achieved.[20]

Adult health

There is evidence from Walsall[14] and Sheffield (Wilson G, unpublished report, 1987) that premature death from cardiovascular disease is more prevalent among traveller gypsies than in the surrounding population, even when this is predominantly working class. Traveller health projects have also noticed widespread smoking among adults.[21] Heller and Peck noted a high incidence of respiratory tract infection, along with chronic skin conditions and ear, nose, throat and eye problems (unpublished report, 1983); although they do not state the prevalence of each condition or analyse their age distribution.

Although there is no reliable adult morbidity data for traveller gypsies in the UK, a recent study of 58 American gypsies showed high rates of hypertension (78%), diabetes (48%), peripheral vascular disease (39%), renal impairment (20%), smoking (86%) and obesity (84%).[22] The authors also noted 14 deaths at a mean age of 48 years. The study has severe limitations, as the sample was not randomly selected. Nevertheless, even if there was a large selection bias, the findings are disturbing. Thomas and colleagues found a high degree of consanguinity, and postulated an important role for heredity in the prevalence of cardiovascular disease in this community.[22] Until prevalence studies are carried out in the UK, we cannot know if these result

are relevant to traveller gypsies in this country. Certainly American gypsies are directly related to European traveller gypsies, most arriving in the USA in the late nineteenth and twentieth centuries, and aspects of their lifestyle and culture[23] are similar to those of British travellers.

A hostile environment

Although some of the studies cited above suggest a hereditary component in the raised morbidity of traveller gypsies, there is consensus among all those concerned with travellers' health — not least travellers themselves — that the main explanation lies in adverse environmental conditions and poverty. Nationally there are not enough permanent sites or resting places for travellers.

This situation has not significantly improved since the introduction of the caravan sites act in 1968, by which local authorities are required to provide specified numbers of authorized sites. There are not enough sites and 3000–4000 caravans are encamped on illegal sites with poor or no facilities, liable to eviction at short notice by police or bailiffs.[5]

Unfortunately, even when a traveller family is on an official local authority site, there is no guarantee of a safe environment. A study carried out by Kent housing officers in 1984 showed six sites on former refuse tips or adjacent to active tips (unpublished report). Pahl and Vaile[12] found that basic amenities were absent on many sites, including official ones, and the provision of basic amenities in East Anglia[9] was equally poor if not worse (Table 2). In Kent about a third of sites have a poor level of cleanliness and safety. Sixty per cent of traveller mothers reported problems in caring for their children because of:

> 'dirt, fast traffic, rats, lack of safe play areas, difficulty drying clothes, overcrowding, mud, dogs, broken glass, the site getting "used up" with toilet holes, lack of education, noises from factories, smells from nearby sewage works..:'[12]

Table 2. Percentage of traveller families without basic amenities on sites in Kent[12] and East Anglia.[9]

	Percentage of families without amenity				
	Water	Electricity	Toilets	Rubbish collection	Postal delivery
Kent ($n = 125$)	14	21	33	25	32
East Anglia ($n = 123$)	30	—[a]	58	—[a]	35

n = total number of families. [a]No data available.

In addition there are other potential hazards which parents may not be aware of. In 1980 a survey of the Westway gypsy caravan site in west London demonstrated dangerous airborne and soil lead levels.[11] Despite this report, the site remains open. Conditions on many traveller sites are comparable to shanty towns in the developing world. Even a World Health Organization target for 1990 that everyone should have access to safe drinking water will not be reached for travellers in the UK. Women travellers are increasingly 'trailer-bound' and an increased proportion of men are dependent on social security.[21] As in the wider world, there is a polarization between the relatively well off and the poor. This growth of poverty among traveller gypsies has a detrimental effect on health.

The main obstacle to the provision of adequate sites for the travelling community is local opposition.[24] Applications for planning permission for private or local authority sites are fiercely contested. Travellers are therefore forced to camp illegally with no facilities and the resulting state of the site confirms the negative image of travellers held by local people.

A consideration of environmental conditions needs to go beyond the physical environment. Gypsies have always been a persecuted minority in Europe. For more than two centuries, until 1783, gypsies were excluded from the UK and on discovery were punished with the death penalty. More recently gypsies were actively exterminated in Nazi Europe.[25] Although this extreme form of oppression no longer exists, traveller gypsies are still physically attacked,[26] beseiged[27] and shot at.[28] This hostility from the surrounding community and the constant threat of sudden eviction when illegally encamped must have a detrimental effect on mental and physical health,[29] aside from its damaging effect on the continuity of health care.[13]

Although perceived by the settled population as outsiders and intruders, many contested urban and rural areas where travellers camp have been traditional stopping places for more than a century.[30] Throughout this time travellers have occupied a marginal but valuable economic niche.[2]

Access to health care

Health care is not necessarily a major determinant of health status, but

> 'inequality in the availability and use of health services in relation to need is in itself socially unjust and requires alleviation'[31]

All the evidence suggests that poor access to primary health care is a major problem for travellers. However, there are several innovative traveller health projects which seek to rectify this problem.[14,32]

There is general agreement in the literature that many general practitioners do not accept traveller gypsies as patients.[33-35] Linthwaite, in a postal questionnaire to general practitioners in East Anglia found that 27 out of the 45 who responded did not accept travellers on their lists.[9] This result is difficult to interpret because the sample was non-random and it is not clear whether the responding general practitioners would see the travellers as temporary residents. A survey of general practitioners in east London (97% response rate) showed that 10% of practices would not accept travellers at all.[36] As a consequence travellers may often travel great distances to attend general practitioners who are sympathetic. Pahl and Vaile found that 19% of their sample had a general practitioner more than five miles away, and 5% travelled more than 20 miles.[12]

General practitioners are not alone when it comes to turning traveller gypsies away. Health visitors dealing with travellers also report hostility towards travellers in antenatal and child health clinics.[37] Discrimination against travellers directly contravenes the race relations act, but even if all general practitioners and clinics welcomed travellers, there would remain other barriers to good health care arising from the mobility of travellers, different cultural perceptions of illness and time keeping, illiteracy, absence of postal services and absence of medical records.

To overcome these barriers and provide an acceptable level of health care, health authorities need to plan services and actively seek out traveller gypsies, especially those who are not on permanent sites. In an early analysis of health care for travellers, Sampson and Stockford[13] wrote to all area health authorities (as they were then) for information on how they catered for the health care of traveller families; they found scant evidence of planning. Although a few area health authorities tried to plan services for travel er gypsies, initiated multi-disciplinary teams and even provided mobile health clinics, the majority did not recognize that there was a problem to be solved. Seven years later, in a questionnaire to directors of community nursing services, in all 191 English district health authorities (87% response), Hussey found that the situation had not improved.[38] Only 11

districts had any kind of outreach or special maternity facilities for travellers, although 50 had a designated person with responsibility for travellers' health care. Of the 158 districts with a general policy on prevention or health promotion, only five mentioned travellers.

Travellers' health visitors

Although the national picture of health care for traveller gypsies still looks bleak, there are a growing number of specialist health visitors and health projects concerned with the health of traveller gypsies'. While travellers' health visitors are sometimes part of a mobile team including a community medical officer,[33] they often work in relative isolation.[39] The nursing literature contains vivid accounts of their work, although there has been little evaluation of effectiveness. The approach of these workers was initially an adaptation of the traditional health visitor role, focusing on preventive health care of young children with an agenda of health education for mothers.[32] This was often not successful. Peck writes:

> 'I sometimes feel that I have lost my way as a health visitor, as the last thing a young gypsy mother wants to hear about is preventive medicine or health education. She wants help getting the smashed window replaced in her trailer and sufficient money to buy food for her family and do her washing at the launderette. Above all, she would like a stopping place for the trailer, without fear of harassment from the local residents or local authority.'[40]

The most interesting development in traveller health care is the adoption of a patient centred approach,[14,41,42] starting from travellers' concerns and problems. This considerably broadens the role of the travellers' health visitor. He or she becomes an advocate who mediates between travellers and health professionals, as well as local authorities and social security officers.

There is a shift from providing 'special' health and preventive services directly to travellers, to helping them integrate into existing facilities. Liaison with and education of general practitioners is an important part of this work. In this light it is disappointing to find that in east London, where a travellers' health visitor has been in post since 1981, 10 out of 25 practices who had seen traveller patients over a one year period, did not know of the health visitor's existence.[36]

The challenge to general practitioners

As general practitioners we do not have any direct influence on local site provision or the environmental conditions which undermine the health of our traveller patients. Nevertheless, we can publicly support demands for secure and safe caravan sites.

At the level of health authority policy making, general practitioners with traveller patients should request the appointment of a designated travellers' health visitor, if one does not already exist. Aside from his or her other roles the health visitor can help in the follow-up of traveller patients, particularly when literacy is a problem and postal services are absent.

A travellers' health visitor encourages general practitioners to move from a reactive position dealing only with acute health crises towards the provision of preventive health care for travellers. A travellers' health visitor can also help general practitioners negotiate some of the cultural differences between doctors and their traveller patients, who often have their own concepts of hygiene and illness.

Problems with continuity of care and lack of medical records in such a mobile population have prompted projects to introduce hand-held family health record cards in Sheffield, Kent, Walsall, east London and East Anglia. Although these cards have not yet been formally evaluated, initial enthusiasm has been dampened because many general practitioners are not aware of their existence and do not request them from their traveller patients.[43] In view of evidence for low immunization uptake, increased cardiovascular risk factors and perinatal problems, general practitioners should initiate opportunistic screening whenever travellers consult them.

Although general practitioners should aim to integrate traveller patients into the normal health care system, there will always be a need for 'outreach' work, particularly on temporary sites and with the more mobile travellers. Every health authority with a traveller population needs to coordinate this work, which will sometimes be undertaken by community medical officers and sometimes by general practitioners in conjunction with travellers' health visitors. Training for these professionals is essential if their intervention is to be successful. Any health or preventive initiative should be based on close consultation with the local traveller communities, who are best placed to identify specific problems.

Improving primary care for travellers is a challenge to our flexibility as general practitioners, and a real test of our ability to provide a non-judgemental, patient-centred service. Travellers are not the only group whose health needs require a specific response. The skills we acquire will strengthen our work with other groups who currently are not well served by the health service, such as other ethnic minorities[44] and the homeless.[45]

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Maternity Alliance, 15 Britannia Street, London WC1X 9JP.

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Traveller Gypsies and childhood immunization: a study in east London

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SUMMARY. The immunization status of the children of Traveller Gypsies presenting to two general practices and a paediatric accident and emergency department in east London between July 1988 and February 1990 was compared with that of a control group presenting to the same services. Study of parental reports and other records for 72 Traveller Gypsy children and 106 control children aged 10 months to six years revealed that Traveller Gypsy children had significantly lower completion rates for pertussis, measles, diphtheria/tetanus and poliomyelitis vaccines than the control group. The difference between the uptake of the first and third diphtheria/tetanus, pertussis and poliomyelitis vaccines was significantly greater among the Traveller Gypsy children than among the control group. The low immunization rates are due to poor access to services as well as rejection of certain vaccines by Traveller Gypsies. The 1990 general practitioner contract and reforms to the health service may result in decreased access for Traveller Gypsies unless steps are taken by family health services and district health authorities to meet the health care needs of this group. Possible solutions to this problem include outreach services to caravan sites, opportunistic immunization, better records and targeted health education.

Keywords: immunization status; Traveller Gypsies; children and infants; access to health care.

Introduction

TRAVELLER Gypsies are one of the oldest ethnic minorities in the United Kingdom. Their access to health care and use of preventive services are rarely investigated, but most reports suggest they are poorly served by health authorities and general practitioners [2] Only two large surveys of immunization among the children of Traveller Gypsies h ve been carried out and both have shown low completion rates [4] Both studies were carried out in rural areas, relied exclus vely on parental recall of immunization status and did not include local control groups.[5] Reasons for low immunization rates among Traveller Gypsies have not been investigated and it cannot be assumed that parental resistance is the most important factor Barriers to uptake of immu nization and other preventive services for Traveller Gypsies include discrimination from doctors, enf rced mobility, non literacy and the absence of postal addresses for recall.

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This study was part of a larger project to assess the health care of Traveller Gypsies in Hackney, east London. As one measure of preventive health care provision the immunization status of Traveller Gypsy children presenting to primary care services was assessed and compared with that of a control group.

Traveller Gypsies have stopped in Hackney for at least 150 years.[7] There are no official caravan sites in the borough but there is one 'tolerated site' containing a dozen pitches and many areas of waste ground where Traveller Gypsies stop until a court order moves them on. A specialist health visitor post for Travel ler Gypsies was created in 1981[8] and since 1986 the post-holder's priority has been to encourage Traveller Gypsies to use existing primary care services, rather than providing services such as immunization on caravan sites.[9] The local settled popula tion from which the control group for this study was drawn is made up of many ethnic groups with a high proportion of low income and single parent families.[10]

Method

Consecutive Traveller Gypsy children aged 10 months to six years presenting to the accident and emergency department at the Queen Elizabeth Hospital for Children or to any of the 12 general practitioners working at two practices in Hackney between July 1988 and February 1990 were recruited. A survey of all practices in Hackney and Tower Hamlets [1] identified seven which reported seeing at least one Traveller Gypsy patient per week — two of these practices agreed to participate in data collection. The only paediatric accident and emergency department in east London is sited at the Queen Elizabeth Hospital for Children in Hackney. Cases were children whose parents gave a caravan site as a home address or whose notes contained a previous caravan site address or who were known by the receptionists or nurses to be part of a Traveller Gypsy family. Recruitment of controls differed in the two settings. In the accident and emergency department nurses were asked to recruit the next two children who were not Traveller Gypsies seen after a Traveller Gypsy child had been recruited. In the general practices two sex-matched children with the nearest birth date to the Traveller Gypsy child were selected from the practice register. Doctors were asked to take the immunization history from the parents at the next consultation and this was indicated by attaching a data entry card to the front of the notes.

Nursing staff at the accident and emergency department and general practitioners in the participating practices were asked to comp ete a data entry card with the parental report of the immunization status of the children. Before data were transferred from the data entry cards, the child's name and date of birth were checked against a list of all children recruited from the three cen tres. Where a ch ld was recruited by two sites on y the data fr m the most recent contact was used. Other records of immunization status were obt ined from the health authority computerized records, practice based child health records and records kept by the specialist health visitor for Trave ler Gypsies. If more than one record of immunization status was available that which contained the most recent information was used for comparison with parental recall.

Children were classified as not having had an immunization when they were not immunized one month or more beyond the date recommended in the immunization schedule used in

Hackney during the study period. The three, seven and nine month schedule for the diphtheria, tetanus and pertussis and poliomyelitis vaccines and the 15 month measles schedule were in use at the time of the study In April 1989 the measles vaccine was replaced with the measles/mumps/rubella vaccine and data on both vaccines were coded together.

Statistical analysis

Differences between groups were assessed using confidence interval and chi square testing using *CIA (Confidence interval analysis)* and *SPSS* programmes. A kappa statistic was calculated for Traveller Gypsy and control children as a measure of agreement between parental reports and records. The McNemar test was used to assess whether there was a bias towards 'under reporting' or 'over reporting' from parental or other sources. Neither the kappa statistic nor the McNemar test assumes that the parental or other reports are correct, they simply provide an index of agreement or disagreement.[12]

Results

Immunization status was determined for a total of 72 Traveller Gypsy and 106 control children eligible for completion of the triple antigen plus poliomyelitis vaccines. Of these children 61 and 85, respectively, were also eligible for the measles or measle/mumps/rubella vaccines. The two groups had similar age–sex distributions. In the two general practices 87% of eligible Traveller Gypsy children seen in the study period were recruited, whereas in the hospital only 51% of the eligible Traveller Gypsy children were recruited. In the practice and hospital groups Traveller Gypsy children who were not recruited had similar age–sex distributions to the recruited samples. Seventy per cent of potential controls were recruited in the general practices and 81% in the accident and emergency department.

Validation of parental reports

Using all available sources of data it was possible to assess independently the immunization status of 19 of the 48 Traveller Gypsy children recruited in the general practices (40%) and six of the 24 children recruited in the accident and emergency department (25%). Immunization records were available for 53 of the 67 control children seen in the practices (79%). For the hospital sample information was available on nine of the 39 control children (23%).

The kappa statistic showed substantial agreement (0.6 or greater) between parental recall and immunization records for all immunizations except the first pertussis immunization for Traveller Gypsies where the agreement was fair (0.5) (full table of parental report validation data available from the authors). The McNemar test only produced a significant result for the first pertussis immunization for Traveller Gypsies, where it indicated a bias towards under reporting of the immunization by the parents, or over reporting in the records ($P<0.05$).

Immunization rates

Table 1 shows that the completion rates for the primary course of all types of immunization were significantly lower among the Traveller Gypsy children than among the control children. A general practitioner's name was given for four of the 24 Traveller Gypsy children recruited in the accident and emergency department (17%) and 35 of the 39 control children (90%). The rates for the completion of the primary course for Traveller Gypsy children recruited to the study in general practice and the accident and emergency department are shown in Table 2. Although absolute completion rates for all components of the primary course were consistently higher in Traveller Gypsy children recruited in general practice than in hospital, these differences were not statistically significant. With this sample size a type II error is possible in the sub group comparison of immunization completion by place of recruitment. For example, a sample of 350 Traveller Gypsy children would have been required to detect a real difference of 15% in poliomyelitis completion rates between children recruited in general practice and the accident and emergency department, with a power of 0.85 at a 0.05 significance level.

Table 1. Percentage of children completing the primary course of immunization (parental reports).

	% of children completing course		
	Traveller Gypsies ($n = 72$)	Controls ($n = 106$)	Difference (95% CI)
Pertussis	*15*	*71*	*56 (44 to 68)****
Diphtheria/ tetanus	*33*	*85*	*52 (39 to 64)****
Poliomyelitis	*31*	*87*	*56 (44 to 69)****
Measles MMR[a]	*20*	*71*	*51 (38 to 65)****

n = total number of children in group. CI = confidence interval. MMR = measles/mumps/rubella. [a] $n = 61$ for Traveller Gypsies, 85 for controls. ***$P<0.001$ (chi square test, one degree of freedom).

Figure 1 shows that the completion rate for the primary tetanus and diphtheria immunization rose throughout the age range studied for Traveller Gypsy children but was static by two and a half years of age for controls (poliomyelitis immunization followed a similar pattern). The completion rate for pertussis immunization was approximately static by two years of age for both groups of children.

Table 3 shows the proportion of Traveller Gypsy and control children who had the first immunization but did not complete the primary course. Both groups have a 'fall off' between the first and third immunizations for all the components of the primary course, but this was significantly greater for Traveller Gypsy children than for the control group.

Discussion

In this sample of Traveller Gypsy children presenting to primary care services in an inner city area the completion rate for the diphtheria/tetanus and poliomyelitis vaccines was poor, with an even lower rate for the pertussis and measles vaccines. Although the absolute completion rates for all components of the primary immunization course were higher in the Traveller Gypsy children recruited in the two practices than among those recruited in the accident and emergency department, these differences were not significant at the 5% level. It is disappointing that use of a general practice did not result in an increased completion of the primary course of this order The majority of Traveller Gypsy children recruited in the accident and emergency department did not have enough contact with a general practice for their parents to give the name of a practitioner.

One reason for the low completion rates found in this study may be that the sample was unrepresentative. Two thirds of the sample of Traveller Gypsy children in this study were attending general practice and may not therefore be representative of all Traveller Gypsy children living in Hackney. However, it is unlikely that children who have less contact with primary care services would have a higher uptake of immunization Another reason for the low rates may be that both parental recall and district child health record systems are unreliable. It cannot be assumed that other records provide a 'gold standard' against which parental recall can be judged. [3] Nevertheless, concordance

Table 2. Percentage of Traveller Gypsy chi dren completing the primary course of immunization recruited in the two general practices and the hospital accident and emergency department.

	% of Traveller Gypsy children completing course		
	General practice (n = 48)[a]	Hospital (n = 24)[b]	Difference (95% CI)
Pertussis	*19*	*8*	*10 (-5 to 26)*
Diphtheria/tetanus	*38*	*25*	*13 (-10 to 35)*
Poliomye itis	*35*	*21*	*15 (-7 to 36)*
Measles MMR	*22*	*15*	*7 (-13 to 27)*

n total number of children in group CI = conf dence interval. MMR = measles mumps/rubella. For measles/MMR: [a]n = 41; [b]n = 20.

Table 3. Percentage of children having first immunization but not completing primary course of immunization.

	% of children not completing course (total no. having first immunization)		
	Traveller Gypsies	Controls	Difference (95% CI)
Pertussis	*42* (19)	*12* (85)	*32 (7 to 54)***
Diphtheria/tetanus	*53* (51)	*13* (104)	*39 (24 to 55)****
Poliomyelitis	*54* (48)	*12* (104)	*43 (27 to 58)****

CI = conf dence interval. **P<0 01; ***P<0 001 (chi square test, one degree of freedom).

between parental and other reports was good, so it is unlikely that the low completion rates described here are artefactual.

Only 26% of Traveller Gypsy children had their first pertussis immunization and 20% their measles immunization which suggests a larger role for parental choice with these vaccines than with diphtheria/tetanus and poliomyelitis vaccines (71% and 67%, respectively, had first immunization). Subsequent interviews with 28 Traveller Gypsy parents whose children were part of the immunization study suggested that they considered pertus sis and measles to be 'normal' or even 'strengthening' for their children, and different from poliomyelitis, tetanus and diphtheria (unpublished data). They also expressed strong views about the pertussis vaccine causing fits and brain damage. While other ethnic minorities may have been shielded from the effects of adverse media publicity by language barriers,[14] television programmes in the 1970s on the putative dangers of pertussis vaccine may have reinforced long held concerns of Trave ler Gypsies about the dangers of immunization. The low literacy rate among Traveller Gypsies throughout Europe, [5] suggests that written health education materials will have a neglig ble impact. Additional support for immunization initiatives may come from local Traveller Gypsy representatives, who have facilitated uptake in the past.[16]

Increasing the uptake of pertussis vaccine among Trave ler Gypsies could prove difficult, as its rejection may have become part of the symbolic boundary distinguishing Trave ler Gypsies and settled people. As described by Okley[1] this boundary consists of pollution taboos and other beliefs which allow Trave ler Gypsies to define themselves as separate and different from the dominant society

In this study over two thirds of Traveller Gypsy children had the first diphtheria/tetanus and poliomyelitis vaccines. Their parents, thus had no objections in principle to these vaccines and therefore the uptake of the first immunization in the course repre sents a minimum level of completion if access to immunization services were improved. The fact that completion rates for these vaccines continue to rise as Traveller Gypsy children get older supports this hypothesis. Factors which reduce Traveller Gypsies' access to immunizations include involuntary mob ity, lack of a general practitioner and lack of information about community health services.[26] These factors are not usually problems for the settled community, where parental attitude is the main determinant of immunization uptake,[1] although they may be

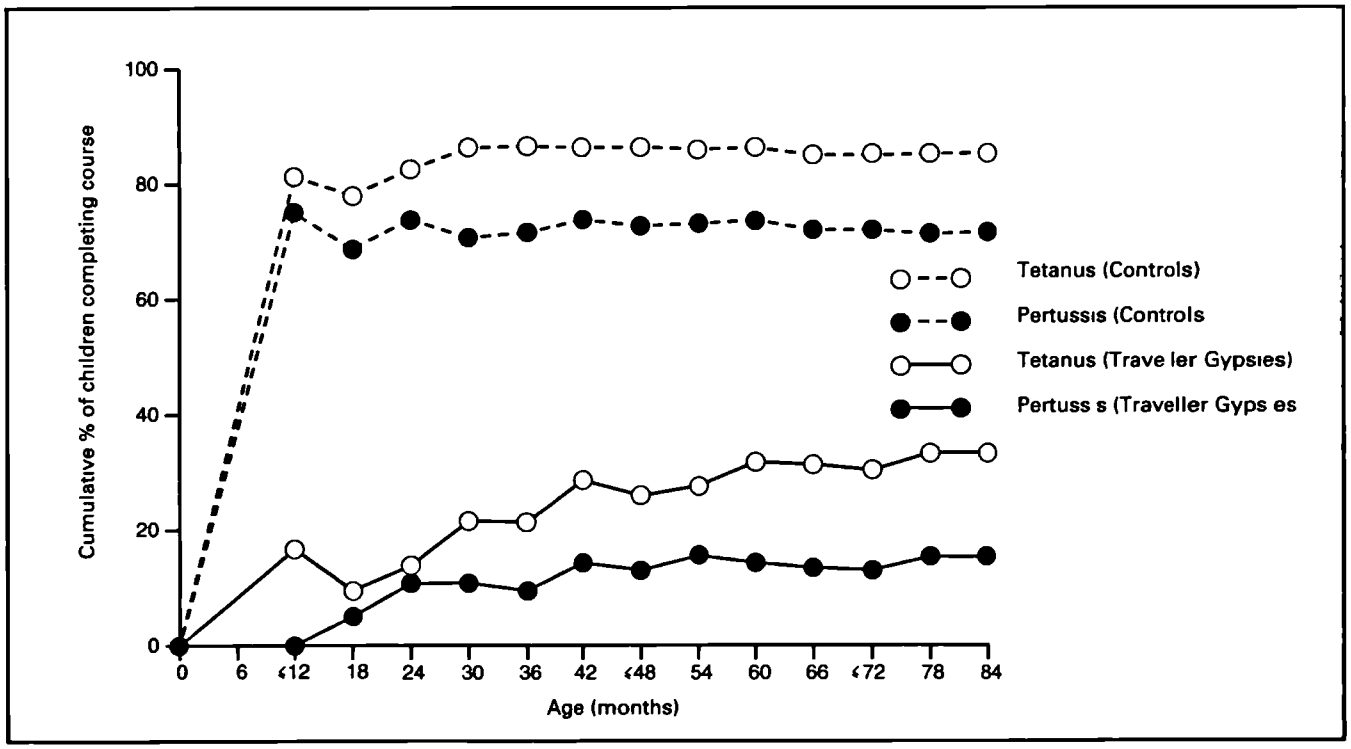

Figure 1. *Completion of primary tetanus (and diphtheria) and pertussis immunizations for the Traveller Gypsy and contro children.*

important for homeles families in bed and breakfast accommo dation. [8]

This study was completed before the imposition of the new general practitioner c ntract in April 1990. There was already evidence that some general practitioners would not register Traveller Gypsy patie s, even as temporary residents, and the targets in the contract provide a further disincentive. [9] Another consequence of the new contract is the removal of financial incentives to offer o portunistic immunizations to Traveller Gypsies seen as temporary residents. As a result of this study, the City and East London Family Health Services Authority has introduced an item of service payment to general practitioners to encourage the immun ation of mobile Traveller Gypsy children who are not registered with practices.

The new structure of the health service may also have unfortunate consequences f r Traveller Gypsies. Each purchasing authority is responsib e for its resident population and Traveller Gypsies do not easil fit into this category. The size of the Traveller Gypsy community in any area is difficult to determine and its age structure i usually unknown, making needs assessment and contracting problematic. The provision of spec alist health visitors for T aveller Gypsies is already patchy[2] and existing posts have already been cut. For example, in April 1992 Bloomsbury and Isling on Health Authority in London withdrew its funding for a hea th visitor for Traveller Gypsies (personal communication).

The following recommendations can be made. Systematic out reach should bring immunization and other preventive services to caravan sites if immunization rates are to improve. Opportunistic immunizations of Tra eller Gypsy children presenting to general practitioners and accident and emergency department staff with accidents or non-febrile illnesses, or of siblings accompanying an ill child should be encouraged. Parent held records should be used to supplement parental recall of immunizations and other child health informat on. Family health services and district health authorities should encourage practices to register their Traveller Gypsy patie s by funding specialist health visitors and compensating for any loss of income resulting from missing immunization targets. Appropriate health education material for Traveller Gypsies shou d be produced in collaboration with par ents who have accepted these immunizations, taking account of cultural and literacy barriers. To date there is no appropriate material from the Hea th Education Authority despite its commitment to ethnic minority needs.

In our enthusiasm give immunizations, we must not lose sight of the right f a parent to refuse specific vaccines for their child. Refusal to have a child immunized may be a rational choice for an ind vidual parent, although not in the interests of Traveller Gypsies as a group. [4 25] In the last outbreak of paralytic poliomyelitis in Eng and and Wales, 20 of the 26 cases were among people that were not vaccinated and at least six of these were Traveller Gypsies [6]

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Current Comment

(xxii) Traveller-Gypsies and general practitioners in East London: the role of the Traveller health visitor

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Summary
Traveller Gypsy communities in the United Kingdom (UK) have higher morbidity and mortality levels than the national average[1] and their members have only limited access to primary and preventative health care services in most areas.[2,3] Results of a questionnaire survey of general practitioners (GPs) in East London support previous evidence[4] that the appointment of specially trained health visitors could help improve levels of understanding between GPs and Traveller families and so help Travellers make more effective use of conventional local primary care networks. The relevance of this specific example for other minority populations is evident.

Introduction
In 1987, Hussey found that 81 of 191 district health authorities (DHAs) employed specially trained health visitors to deal exclusively with Traveller-Gypsies. The actual number so employed is not known In some districts, the health visitor is part of a team which, with a clinical medical officer, provides primary health care from a caravan parked on Traveller sites.[6] The transitional nature of such 'out-reach' services detracts from their long term efficacy and there is a need to integrate Travellers into established primary care networks.

Integration cannot be achieved without co operation from GPs and personnel in community health centres. Unfortunately, widespread anecdotal reports[7,8] suggest that many GPs are reluctant, or actually refuse, to accept Travellers as patients As a result they often turn for help to accident and emergency departments

In 1981, a Traveller health v sitor was appointed to East London Part of her main remit was to help Travellers use local primary care services She now has an enormous case load[9] covering a highly mobile population of 1,800–2,100 Trave lers in four health authorities.

The questionnaire survey
In June 1988, as part of an initiative to improve health care for Trave lers, questionnaires were sent to all 103 general pract ces in Tower Hamlets and Hackney, East London. The aim was to determ ne:

i. what proport on of pract ces accepted Traveller patients;

ii. which practices knew that the Traveller health visitor existed

iii. what problems, if any, GPs experienced in providing hea th care for Travellers.

Forty six non responders were sent a repeat questionnaire wh ch was then followed up by telephone

The mo t frequent comp a nts expressed by the 25 pract ces which had seen Trave ler patients n the past year were related to problems of continuity, follow-up and keeping appointments.

Twenty practices said that they lacked information about past medical histories, and 21 wanted more information about Traveller culture.

Table 1: *Response to questionnaire*

A *Survey*		
General practices which:		
i. received questionnaires	103	
ii. responded (by form or telephone)	100	(ie 97%)
B *Results*		
General practices which:		
i. accepted Travellers	90	
ii. had seen Traveller patients in the past 12 months	25	
iii. had treated one or more Traveller patients per month	11	
iv. were aware of the Traveller health visitor	10	(of the 25 at (ii))

Comment
The delivery of good primary health care to Travellers or any other marginalised group, requires improved access to GP services [1] Problems of access from the Travellers' *and* GP's perspectives must be identified, and close co-operation encouraged between Traveller health visitors and local GPs. This study suggests that at least 10 per cent of practices in East London do not accept Travellers as patients, or as temporary residents. This perhaps reflects levels of discrimination in the community.[11]

Although caravan sites are spread relatively uniformly over Tower Hamlets and Hackney, only 11 practices treated more than one Traveller a month. The only other similar survey,[12] one carried out in East Anglia, showed that 27 of 45 practices d d not accept Travellers, but this result is unreliable as (i) the sample is non-random and (ii) no indication is given as to whether the responding GPs would see Travellers as temporary residents.

More than one third of practices which had seen Travellers in the past year were ignorant of the existence of the Travelers' health visitor Greater publicity about their role is essent al. The problems of poor continuity and follow-up, as well as the absence of a past medical history for many Travellers, are partly addressed by the provision of hand-held record cards. Originally devised in Sheffield, cards are being prov ded by various projects for their Traveller clients. The quest onnaire results prompted us to introduce a card for patients seen in East London.

Many doctors who see Travellers in East London felt that more information about their culture would decrease discrimination and improve the standard of health care provided. Most accounts of Traveller health care emphasise this point.[1,6] Discuss ons of their health care perception, priorities, and cultural concepts of hygiene could be included in postgraduate meetings in the presence of the local Traveller hea th v sitor. Informal discussions with Traveller patients could be equally, if not more, enlightening.

The survey shows that the appointment of a Traveller hea th v s tor does not automatically improve access to primary care. Health authorities and fami y practitioner committees (FPCs) need to recognise the problem and encourage GPs to take responsibility for Travellers in their area It would seem essent al also that Travellers themselves be taught to better understand what services are available and what may be expected by and of users of these services. The role of the Travel er

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Health Visitor in educating both providers and recipients is apparent, and highlights the value of such professionals in situations where minority groups form a significant proportion of the population.

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Introducing:
(i) New UK mutagenicity guidelines

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The Committee on the Mutagenicity of Chemicals in Food, Consumer Products and the Environment provides expert advice to Government departments. Professor Bryn Bridges, Director of the Medical Research Council (MRC) Cell Mutation Unit, is Chairman and the specialists in human genetics, metabolism, and genetic toxicology are appointed by the Chief Medical Officer.

The Committee produced its first guidelines on the testing of chemicals for mutagenicity in 1981, but rapid developments in genetic toxicology prompted the preparation of a revised version published this year[1]. The Committee's advice is used by regulatory agencies, for drawing up testing requirements and interpreting the results of mutagenicity tests.

The new guidelines set out to be an informative document, not merely a compendium of recommended tests. Chapter 3 for example, entitled 'DNA, Genes and Chromosomes' gives background information and recalls present knowledge of genetic processes and mechanisms, and of the role of DNA, since this is fundamental in genetic toxicology.

From the physician's point of view, the hazards associated with mutagenic chemicals are twofold. Firstly, they can induce mutational changes in reproductive cells, giving rise to lethal effects, or to genetic diseases (or other health detriments) in offspring. The range of disorders which can result from abnormalities in the genetic material in humans is extremely wide. It includes conditions produced by changes in single genes (eg cystic fibrosis and the haemoglobinopathies); those caused by chromosome abnormalities (eg Down syndrome); and those possessing a genetic component (eg congenital malformations, diabetes mellitus, schizophrenia). The single-gene defects alone comprise a very large group of serious conditions which include the autosomal dominant disorders (2 per 1,000 live births) such as retinoblastoma, Huntington chorea, Gardner syndrome and multiple intestinal polyposis; autosomal recessive disorders (2.4 per 1,000) such as childhood blindness, severe childhood deafness and phenylketonuria—as well as the sex-linked disorders (0.8 per 1,000) such as Duchenne muscular dystrophy and haemophilia A and B. Chromosome abnormalities affect 6.7 per 1,000 live births: these include instances of Patau syndrome, Edwards syndrome and Klinefelter syndrome. In addition, chromosome abnormalities constitute a major cause of fetal death and spontaneous abortion (15–20% of recognised pregnancies are affected by chromosome abnormalities). In the absence of quantitative data, it is prudent to assume that mutagenic chemicals have the potential to induce new mutations in humans which contribute to the spontaneous incidence of some or all of the conditions; the extent to which this occurs, if it does, is unknown.

The guidelines consider genetic and partly genetic diseases in humans and describe their type, frequency and mutation rates. The data clearly indicate the important role of genetic abnormality in causing ill-health in humans. Chapter 6 is concerned with three aspects of the monitoring of human populations: ways of monitoring human populations for heritable germ cell mutations for genotoxic effects in somatic and germ cells, and for other evidence of exposure to mutagenic compounds. The latter two approaches are increasingly important as biological indicators of exposure to, and uptake of, potentially mutagenic compounds.

Secondly, mutagenic chemicals can endanger health by inducing mutational changes in somatic cells, which increase the possibility of neoplastic transformation. The implications of mutagenicity data for carcinogenicity are considered in Chapter 4. The discoveries that gene and chromosomal mutations can cause act vation of proto-oncogenes and inactivation of tumour suppressor genes shows that mutation is of fundamental importance in the carcinogenic process. How-